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Children

ABSTRACT

Twelve issues of "Exceptional Parent" magazine provide a variety of articles and resources on parenting the child or young adult with a disability. The January issue is a resource guide with directories of national organizations, associations, products, and services. The February issue focuses on early childhood, including assessment, day care, and transitions. The March issue's emphasis is on mobility and considers rehabilitation technology and power/manual wheelchairs. The main topic of the April issue is summer, focusing on vacations, planning, and travel ideas. The May focus is on communication, including facilitated communication, augmentative communication, hearing aids, and using the telephone. The June issue deals with recreation, including the World Games, Special Olympics, and recreation resources. Friendship and community is the featured topic of the July issue. The emphasis of the August issue is on health, including genetic counseling, teaching doctors to communicate, and rhizotomy. The September issue features education, with articles on quality, inclusion, and the Individuals with Disabilities Education Act. October articles are on toy selection, ramps and lifts, and diagnostic labels. Technology is the iocus of the November issue. The December issue's emphasis is on family, especially grandparents, estate planning, and the extended family. (DB)

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JANUART 1995

EXCEPTIONAL DARRENT

The Magazine for Families and Professionals

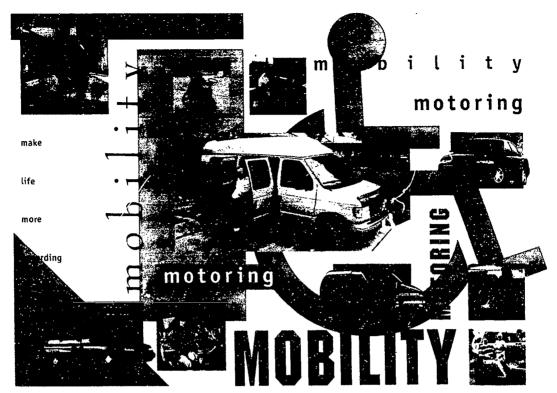
1995 RESOURCE GUIDE

DIRECTORIES OF NATIONAL ORGANIZATIONS,
ASSOCIATIONS, PRODUCTS & SERVICES



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Publisher's Letter

Dear Reader and Advertiser,

Thank you! The year 1994 was wonderful for Exceptional Parent and it was made possible by you!

As we move into our 24th year, I would like to share some thoughts about the changes taking place in health care and about the impact these changes will have on our readers—the families, health care professionals, and educators that we serve—and on our magazine.

One important change is that today's health care consumers are becoming empowered as never before. Physicians, therapists, nurses, and teachers recognize that they need to *collaborate* with parents. Professionals know they must think of family members who deal with the day-to-day challenges of raising a child or young adult with a disability or special health care need. Moreover, as the number of new treatment therapies increases, so does the need for information to help families and professionals make informed choices and work together more effectively.

Exceptional Parent is moving forward to help meet these needs. You already may have noticed that the inscription inside our logo reads, "Parenting Your Child or Young Adult with a Disability," and that our new "tag line" says, "The Magazine for Families and Professionals." These changes reflect the expanding scope of our magazine. They also point to our commitment to provide even more opportunity for parents, health care professionals, and educators to share ideas and experiences, to learn from one another, and thereby better serve the needs of children and young adults.

For example, our 1995 Annual Resource Guide contains a new feature. Articles that appeared in 1994 and that are of particular interest to professionals involved in the care and treatment of children and young adults with disabilities or special health care needs are now specifically identified in the Index.

As 1995 begins, we are pleased to point to our efforts to improve communication between the families and professionals we serve. At the same time, we are proud to emphasize that the fundamental mission of *Exceptional Parent* remains unchanged. We will continue to offer *Information that Matters, from People Who Care.* This phrase, as always, represents a statement of our purpose and values—what we stand for, who we are and what we do. We will continue to provide information that helps make a difference in the lives of the people we serve. Moreover, all the members of the various departments in our company recognize the importance of what they do. They do it with a passion and sense of caring and commitment that fills me with emotion and an ongoing sense of pride.

To all our readers, please accept my sincere thanks for a gratifying 1994 and my prayers that 1995 will be a wonderful year for you and your children.

Sincerely yours,

Joseph M. Valenzano Jr. President & Publisher

and M. Valen zan



JANUARY 1995/VOL. 25, ISSUE 1

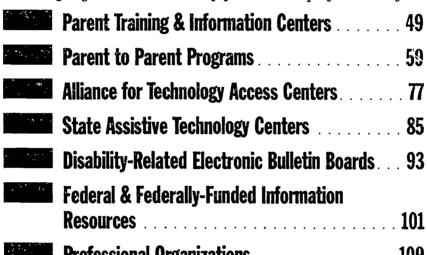
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The Magazine for Families and Professionals

1995 RESOURCE GUIDE

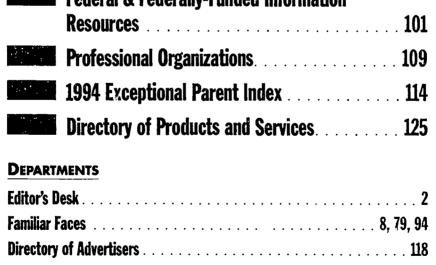
	National Information and Advocacy Resources	. 5
	National Resources for Specific Disabilities and Conditions	15
SPECIAL Matchin	ARTICLE: No Longer Alone by Andrea Kamens	37
5-23-		















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EDITOR'S DESK

elcome to our biggest and most comprehensive annual Resource Guide ever! With the help of organizations large and small, this year's guide includes more information about the services each organization provides.

We have also included many more Canadian groups.



We have worked hard to verify all the information in this guide. Nonetheless, we may have made a few errors. Please do not hesitate to contact us with corrections; we will publish all corrections in future monthly issues.

Some organizations are very large and include paid staff members. Others may be coordinated by one or two dedicated volunteers working nights and weekends from a kitchen table. This year's directory includes a few brief stories about several groups to illustrate the energy and creativity of parents everywhere. We

know each of the hundreds of groups listed has an equally compelling story.

How to use this Resource Guide

Parents can use the directory of National Resources for Specific Disabilities and Conditions to obtain information about specific conditions and to network with parents of similar children. The extensive cross-referencing may help parents find more than one resource for the same condition or disability.

Sources of local assistance can be identified through Parent Training and Information Centers, Parent to Parent Programs, Alliance for Technology Access Centers and State Assistive Technology Programs. Through these local contacts, parents can communicate with caring people knowledgeable about local resources.

Professionals—physicians, social workers, nurses and educators—can use this guide to put parents in touch with national organizations that can provide emotional support and up-to-date information on specific disabilities or conditions. Professionals can also use these organizations to stay informed and involved. By networking with local groups, professionals can help families and colleagues find nearby resources. Local and national organizations may also help professionals find others who share specific clinical or research interests.

This guide also includes an extensive index of topics covered in 1994. To assist professionals, we have marked articles of particular interest to those in the fields of health care and education.

Advertisers

Many companies and service organizations have purchased ads and listings so parents and professionals can find the products and services they need throughout the year. Readers can use the free Product and Service Information cards to obtain detailed information from participating advertisers.

Many years ago, parents and profession: 1s taught us that advertising provides an important service. When Exceptional Parent first started to accept advertising-more than 20 years ago-parents and many professionals on a child's clinical or educational team had little say about product purchases. As a result, they were typically excluded from marketing efforts. But today, parents, along with other members of the child's "team," are key decision-makers. Successful companies now appreciate the need to keep parents and professionals well-informed.

Thank you one and all

This guide could not have been completed without the help of many individuals and groups. We are very grateful. And we have been very pleased to hear from so many about how helpful our previous guides have been in making connections throughout the world. We wish you all the best in the new year.

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Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

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L. Sasso-Lundin, Occupational Therapist, Shriners Hospital, Portland, OR

66ProtectaCop will stay on the child and protect his head. Most children have weak neck muscles. ProtectaCop is so much lighter than other helmets.99

S. Balzer, Physical Therapist, Cottonwood, AZ

66The neurosurgeon loved ProtectaCap. He sent it home with the patient after cranial surgery,99

Methodist Hospital, Son Antonio, TX

66ProtectaCap is the best thing in the world! It's so comfortable. She doesn't take it off her head like the other ones. It really protects her. And it's so cute.

Thank you very much.??

M. Miller, Parent, Lombard, IL

66 Your ProtectaCops are colorful and offer many good features for comfort. We will recommend them to our families. ?? Children's Hospital of Philadelphia, Philadelphia, PA

66My daughter hos a shunt in her head.
ProtectaCap protects it really well. It's wonderful.99

C. Vanderpol, Parent, Bellingham, WA

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understand.

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hese national organizations are information and advocacy resources for families and professionals. This directory starts with a listing of organizations providing general information and advocacy, followed by organizations focusing on more specific areas of concern to the families of children and adolescents with disabilities.

A description of services provided by individual organizations follows each listing. Numbers correspond to items listed in the Key to Services.

This symbol (24) indicates an Internet e-mail address.

General

American Association of University Affiliated Programs for Persons with Developmental Disabilities

8630 Fenton St, Ste 410 Silver Spring, MD 20910 (301) 588-8252 (voice) (301) 588-3319 (TTY) (301) 588-2842 (fax) 2,5,6,7

 Offers referrals to local University Affiliated Programs which provide technical assistance, training and information to service providers to support the independence, productivity and community inclusion of people with developmental disabilities and their families.

Association for Persons with Severe Handicaps

11210 Greenwood Ave N Seattle, WA 98133 (206) 361-8870 (voice) (206) 361-0113 (TTY) (206) 361-9208 (fax) 1,2,3,4,5,6,7; state and regional chapters

 Advocates for comprehensive, high-quality, integrated education and full participation in inclusive community settings that support the same quality of life available to people without disabilities.

Association of Birth Defect Children

827 Irma Ave Orlando, FL 32803 (800) 313-2232 (voice, 24-hour registry line) (407) 245-7035 (voice/fax) 1,3,4,6,7,8

 Offers free parent matching and participation in National Birth Defect Registry. Serves as clearinghouse to provide free information about birth defects, particularly those thought to be associated with exposure to environmental toxins.

Canadian Association for Community Living

4700 Keele St Kinsman Bldg, York University North York, ON Canada M3J 1P3 (416) 661-9611 (voice) (416) 661-2023 (TTY) (416) 661-5701 (fax) 1,2,5,6,7

 Provides very comprehensive disability-information service.
 Maintains large book- and videolending library. Advocates for inclusion and community awareness.

Children's Defense Fund

25 E Street NW Washington, DC 20001 (800) 233-1200 (voice) (202) 628-8787 (voice) (202) 662-3520 (fax) 1,2,3,5,7

 Advocates on behalf of all children, with particular attention to the needs of children who are economically disadvantaged, have disabilities or are members of minority groups. Focus is on programs that affect large numbers of children, rather than on helping individual families.

DIRECT LINK for the disABLED

PO Box 1036 Solvang, CA 93464 (805) 688-1603 (V/TTY) (805) 686-5285 (fax) 1,2,3,4,6

 Provides information and education to people seeking help for any disability- or health-related question. Services provided at no charge to individuals and families.

March of Dimes Birth Defects Foundation

1275 Mamaroneck Ave White Plains, NY 10605 (914) 428-7100 (voice) (914) 428-8203 (fax) 6,7,8

 Provides referrals to specialty health care providers, genetic counselors and support groups across the country. Provides educational information on birth defects, genetics and prenatal care.

National Center for Youth with Disabilities

Box 721
420 Delaware St SE
Minneapolis, MN 55455
(800) 333-6293 (voice)
(612) 626-2825 (voice)
(612) 624-3939 (TTY)
(612) 626-2134 (fax)

concept a concept of the concept

University of Minnesota

 Provides information and technical assistance on issues affecting adolescents with chronic illnesses and disabilities and the transition to adult life.

National Easter Seal Society 230 W Monroe

Chicago, IL 60606 (312) 726-6200 (voice) (312) 726-4258 (TTY) (312) 726-1494 (fax)

₫ eseals@mcs.com 2,3,6,7; disability-awareness curriculum for elementary schools

Affiliates in 500 service locations provide physical and occupational therapy, audiology, camping, recreation, early intervention and vocational programs for children, teens and their families.

Key to Services

- 1. Periodical/newsietter
- 2. Other publications
- 3. Videos
- 4. Networking/matching with other families
- 5. National conferences
- 6. Referrals to local resources
- 7. National advocacy efforts
- 8. Fund research
- 9. Provide electronic computer bulletin board

National Organization on Disability

910 16th St NW, Ste 600 Washington , DC 20006 (800) 248-2253 (voice) (202) 293-5968 (TTY) (202) 293-7999 (fax) 1,2,3,6,7

 Promotes public awareness and supports legislation to improve the lives of people with disabilities. Does not provide any direct services to families.

NPND: National Parent Network on Disabilities

1600 Prince St, Ste 115 Alexandria, VA 22314 (703) 684-6763 (V/TTY) (703) 836-1232 (fax) 1,2,3,5,6,7

 Provides a national presence and voice for parents of children, youth and adults with disabilities. Shares information and resources to promote the power of parents to influence government policy relating to the needs of people with disabilities and their families.



National Vaccine Information Center—Dissatisfied Parents Together

512 W Maple Ave, #206 Vienna, VA 22180 (703) 938-3783 (voice) (703) 938-5768 (fax) 1,2,3,4,7

 Advocates for the prevention of vaccine reactions. Provides information on the Vaccine Injury Compensation Program. Makes legal referrals.

NICHCY: National Information Center for Children and Youth with Disabilities

PO Box 1492 Washington, DC 20013 (800) 695-0285 (V/TTY) (202) 854-8200 (V/TTY) (202) 884-8441 (fax)

1,2,4,6; many publications available in Spanish

 Collects and shares information and ideas that are helpful to children and youth with disabilities and the people who care for and about them. Answers questions, links people with others and share common concerns and helps information flow between people who have it and people who need it. Single copies of all publications are free.

Rural Institute on Disabilities

52 Corbin Hall University of Montana Missoula, MT 59812 (800) 732-0323 (V/TTY) (406) 243-5467 (V/TTY) (406) 243-4730 (fax) 1,2,6,9 (800/961-9610, up to 9600 baud)

 Provides information and referral, lending library of books and videotapes, assistance to children of Vietnam veterans and assistive technology loan/lease program.

STOMP: Specialized Training of Military Parents

c/o Washington PAVE 12208 Pacific Highway SW Tacorna, WA 98499 (800) 298-3543 (voice) (206) 588-1741 (V/TTY) (206) 984-7520 (fax) 1,2,4,6

 Provides information about parental rights and responsibilities in obtaining special educational services for children of military personnel. Provides information about testing and assessment, IEPs and networking with military resources.

World institute on Disability

510 16th St, Ste 100
Oakland, CA 94612-1502
(510) 763-4100 (V/TTY)
(510) 7208-9493 (TTY)
(510) 763-4109 (fax)

wid@wid.org
1,2,6,7

• Public policy, research and training center dedicated to independence for all people with disabilities. Seeks to provide accurate information for public and private policymakers to use in crafting services and policies that support independence and quality of life. Does not provide direct client services.

Adoption

AASK: Adopt a Special Kid

2201 Broadway, Ste 702 Oakland, CA 94612 (510) 451-1748 (voice) (510) 451-2023 (fax) 1,4,6,7

 Adoption agency specializing in the placement of children with disabilities; sliding-scale fee for services. Provides post-adoption support services.

Adoptive Families of America

3333 Highway 100N Minneapolis , MN 55422 (800) 372-3300 (voice) (612) 535-4829 (voice) (612) 535-7808 (fax) 1,2,3,4,5,6,7

 Provides problem-colving assistance and information to members of adoptive families and prospective adoptive families. Promotes the health and welfare of children without permanent families.

Jewish Children's Adoption Network

PO Box 16544 Denver, CO 80216-0544 (303) 573-8113 (voice) (303) 893-1447 (fax) 1,4,6

 Helps both birth and adoptive families find resources to help them parent children with disabilities. Finds adoptive placements for waiting children.

National Adoption Center

1500 Walnut St, Ste 701 Philadelphia, PA 19102 (800) 862-3678 (voice) (215) 735-9988 (voice) (215) 735-9410 (fax)

 Approved adoptive families may register on National Adoption Exchange, a computerized database of waiting minority children and children with disabilities and families hoping to adopt such a child.

National Resource Center for Special Needs Adoption

16250 Northland Dr, Ste 120 Southfield, MI 48075 (810) 443-7080 (voice) (810) 443-7099 (fax) 1,2,3,5,6,7,8

 Provides a forum for adoption practitioners, policymakers and advocates to share knowledge and expertise. Serves as a resource for organizations and professionals through consultation, technical assistance, training and a variety of written and videotaped materials.

Arch/actural Accessibility

Center for Universal Design North Carolina State University School of Design

School of Design Box 8613 Raleigh, NC 27695-8613 (800) 647-6777 (V/TTY, US &

Canada) (919) 515-3082 (V/TTY) (919) 515-3023 (fax) 1,2,6

 Provides design information and assistance to families and individuals with disabilities for construction of new housing and home modifications.

Assistive Technology

Access Unlimited

À

3535 Briarpark Dr, Ste 102 Houston, TX 77042 (800) 848-0311 (713) 781-7441 (713) 781-3550 (fax)

 Resource center for information on assistive technology.

11

Key to Services

- 1. Periodical/newsletter
- 2. Other publications
- 3. Videos
- 4. Networking/matching with other families
- 5. National conferences
- 6. Referrals to local resources
- 7. National advocacy efforts -
- 8. Fund resparch
- 9. Provide electronic computer bulletin board

Activating Children Through Technology

27 Horrabin Hall
Western Illinois University
Macomb, IL 61455
(309) 298-1014 (voice)
(309) 298-2305 (fax)

 Provides training and resource information to families of children, birth to eight years, on integrating technology into Individual educational programs (IEPs).

Child Care

Child Care Plus

Rural Institute on Disabilities 52 N Corbin Hall University of Montana Missoula, MT 59812 (800) 235-4122 (V/TTY) (406) 243-5467 (V/TTY) (406) 243-4730 (fax) 1,2,5,6

 Provides technical assistance, written materials and training for families, child care providers and others who support inclusion in early childhood programs.

SpeciaLink

186 Prince St Sydney, NS Canada B1P 5K5 (800) 840-5465 (voice, Canada only) (902) 562-1662 (voice)

(902) 539-9117 (fax)

sirwin@fox.nstn.ca 1.2.3.4.5.6.7

 Serves as the hub of a 3,000-person network of advucates for inclusive child care and education.
 Provides resources and referrals.
 Promotes inclusive practices, policies and programs across Canada.



Education

National Coalition of Title I/Chapter I Parents

Edmonds School Bldg, Rm 201 9th & D St NE Washington, DC 20002 (202) 547-9286 (voice) (202) 544-2813 (fax) 1,3,5,6,7; scholarship program

· Provides information, training and technical assistance to parents to help them participate in planning, implementing and evaluating local Title I programs.

Employment

Electronic Industries Foundation Project with industry

919 18th St NW, Ste 900 Washington, DC 20006 (202) 955-5815 (voice) (202) 955-5836 (TTY) (202) 955-5837 (fax)

· Provides job placement for persons with disabilities; provides referrals and job-matching services to employers.

Job Accommodation Network

West Virginia University Morgantown, WV 26506-6080 (800) 232-9675 (V/TTY) (800) 526-7234 (V/TTY) (800) 526-2262 (V/TTY; from Canada) 2,3,6,9 (800/342-5526 ID to 9600 baud)

· Provides information about job accommodations, the employability of people with functional limitations and the Americans with Disabilities Act (ADA).

Job Opportunities for the Blind

National Center for the Blind 1800 Johnson St Baltimore, MD 21230 (800) 638-7518 (voice) (410) 659-9314 (voice) (410) 685-5653 (fax) 1,2,5,6,7

• Free information packet. Shares methods and ideas that have helped other blind workers get good jobs. Nationwide networking, reference and referral services

National Industries for the Severely Handicapped

2235 Cedar Ln Vienna, VA 22182 (703) 560-6800 (voice) (703) 849-8916 (fax) 1,2,3,5,6,7

· Provides technical assistance to local rehabilitation providers about employment of people with severe disabilities.

Genetics

Hereditary Disease Foundation

1427 7th St. Ste 2 Santa Monica, CA 90401 (310) 458-4183 (voice) (310) 458-3937 (fax) ™ 75051.3604@compuserve.com 2.3.4.6.7.8

 Supports biomedical research. Focuses on Huntington's disease. but can refer families to support groups for other disorders.

Health Care

Association for the Care of Children's Health

7910 Woodmont Ave. Ste 300 Bethesda, MD 20814 (800) 808-2224, ext 306 (voice) (301) 654-6549, ext 306 (voice) (301) 986-4553 (fax) ACCH@clark.net

1,2,3,4,5,6,7,8

· Organization of family members and multidisciplinary professionals. Advocates for family-centered care for children needing specialized health and developmental services. Offers a forum for information sharing and peer support.

Children's Hospice International

700 Princess St, Lower Level Alexandria, VA 22314 (800) 242-4453 (voice) (703) 684-0330 (voice) (703) 684-0226 (fax) 1,2,3,4,5,6,7

Family Voices

Box 769 Algodones, NM 87001 (505) 867-2368 (voice) (505) 867-6517 (fax) 1.2.7

· National grassroots network of families with children who have special care needs, Gathers, analyzes and provides Information on state and national health care reform from a family perspective.

Parent Care

9041 Colgate St Indianapolis, IN 46268-1210 (317) 872-9913 (voice) (317) 872-0795 (fax) 1,2,4,5,6

· Advocates for family-centered services and provides social, emotional and informational support to families and caregivers involved in neonatal intensive care.

The Center for Children with Chronic Illness and Disability

University of Minnesota Box 721 UMHC 420 Delaware St SE Minneapolis, MN 55455 (612) 626-4032 (voice) (612) 624-3939 (TTY) (612) 626-2134 (fax) ☑ c3id@gold.pc.umn.edu 1,2,3,6,7

· Seeks to increase and apply knowledge that fosters the physical, psychological and social development and competence and well-being c intants, children and adolescents with chronic illnesses and disabilities and their families.

Independent Living

independent Living Research **Utilization Program**

2323 S Shepherd, Ste 1000 Houston, TX 77019 (713) 520-0232 (voice) (713) 520-5136 (TTY) (713) 520-5785 (fax) 1.2.3.6.7

· Collects, synthesizes and disseminates information on independent living (IL) subjects. Maintains directories of IL centers. of people who provide IL technical assistance and of IL support materials.

Legal Assistance

American Bar Association Center on Children and the Law

1800 M St NW. Ste 200 S Washington, DC 20036 (202) 331-2250 (voice) (202) 331-2250 (fax) davidsonha@attmail.com

· Publishes information about legal issues related to children.

DREDF: Disability Rights **Education and Defense Fund**

2212 Sixth St Berkeley, CA 94710 (800) 466-4232 (V/TTY) (510) 644-2555 (V/TTY) (510) 841-8645 (fax) 1.3.6

 National law and policy center dedicated to furthering the civil rights of people with disabilities. Offers training, information and legal advocacy to parents of children with disabilities to help them secure appropriate educational and other services. Offers technical assistance, information and referrals by phone.

National Association of **Protection and Advocacy Systems**

900 2nd St NE, Ste 211 Washington, DC 20002 (202) 408-9514 (voice) (202) 408-9521 (TTY) (202) 408-9520 (fax) HN4537@handsnet.org 1,5,6,7

· Voluntary membership organization of federally-mandated programs advocating for the rights of people with disabilities. Offers referral to programs in each state and territory.

National Center for Law and Deafness

Gallaudet University 800 Florida Ave NÉ Washington, DC 20002 (202) 651-5373 (V/TTY) (202) 651-5381 (fax) 2,6,7

· Develops and provides a variety of legal services and programs to the Deaf community, including representation, counseling, information and education.

Pike institute on Law and Disability

Boston University School of Law 765 Commonwealth Ave Boston, MA 02215-1620 (617) 353-2904 (V/TTY) (617) 353-2906 (fax) hbeyer@bu.edu

1.5.6

· Provides information and referrals in disability-related legal matters. Publishes bi-monthly DISABILITY ADVOCATES BULLETIN.



Rare Disorders

Alliance of Genetic Support Groups

35 Wisconsin Cir, Ste 440 Chevy Chase, MD 20815-7015 (800) 336-4363 (voice) (301) 652-5553 (voice) (301) 654-0171 (fax) 1,2,4,5,7

• Serves as a forum for addressing the needs of individuals and families affected by genetic disorders and as a bridge between consumers and service providers.

Lethbridge Society for Rare Disorders

#2 740 4th Ave S Lethbridge, AB, Canada T1J 0N9 (403) 329-0665 (voice) 1.4.5.6

 Offers networking services and local referrals to people with rare disorders and their families.

MUMS: Mothers United for Moral Support

c/o Julie Gordon 150 Custer St Green Bay, WI 54301 (414) 336-5333 (voice) (414) 339-0995 (fax) 1.4

 National parent-to-parent network matches parents with others whose children have similar rare disorders or conditions.

NORD: National Organization for Rare Disorders

100 Rt 37, P0 Box 8923 New Fairfield, CT 06812-8923 (800) 999-6673 (voice) (203) 746-6518 (voice) (203) 746-6927 (TTY) (203) 746-6481 (fax) 1,2,4,5,8

 Clearinghouse for information about rare disorders. Provides literature explaining disorders (first two disease reports free; \$4 each thereafter) and offers networking of families with similar disorders (for paid members only).

Rehabilitation

Canadian Rehabilitation Council for the Disabled

45 Sheppard Ave E, Ste 801 Willowdale, ON, Canada M2N 5W9

(416) 250-7490 (V/TTY) (416) 229-1371 (fax) 1,2,3,4,5,6,7

 Umbrella organization of Canadian service providers, health professionals and consumer groups. Offers publications, disability-awareness materials and other resources.



Since this photo was taken, 11-year-old Joey Bishop of Aromore, Oklahoma has learned to float without any help from Mom or his inflatable aids. Aside from his aquatic pursuits, Joey enjoys watching movies and baseball, driving his power wheelchair, going out to eat and talking to people using his augmentative communication device. Joey, a seventh-grader, says math and "girls" are his best subjects. Joey has agenesis of the corpus callosum.

Respite Care

ARCH National Resource Center 800 Eastowne Dr, Ste 105 Chapel Hill, NC 27514 (800) 773-5433 (voice) (919) 490-4905 (fax)

• Free national respite-provider locator service through 800-number listed above.

Self-Help

American Self-Help Clearinghouse

St. Clares-Riverside Medical Ctr 6 Hinchman Ave Denville, NJ 07834 (201) 625-9565 (voice) (201) 625-8848 (fax)

edmadara@aol.com 2,4,6

 Provides referrals to support groups and other self-help clearinghouses. Provides information on starting support groups.

National Self-Help Clearinghouse

CUNY Grad School, University Ctr 25 W 43rd St, Rm 620 New York, NY 10036 (212) 354-8525 (voice) (212) 642-1956 (fax) demadara@aol.com

 Provides referrals to support groups and other self-help clearinghouses. Provides information on starting support groups and outreach to the public and professionals.

Sexuality

Sex Information and Education Council of the US

130 W 42nd St, Ste 2500 New York, NY 10036-7901 (212) 819-9770 (voice) (212) 819-9776 (fax) 1.2.6

• Library has 5,000 volumes and more than 10,000 indexed articles on sexuality. Collects extensively in the area of sexuality and disability. Does database searches to find books and articles of interest.

Sibling Support

Sibling Information Network

The A.J. Pappanikou Center on Special Education and Rehabilitation 62 Washington St Middletown, CT 06457 (203) 648-1205 (voice) (203) 644-2031 (fax)

1,2
• Clearinghouse of information related to siblings of individuals with disabilities.

Key to Services

- 1. Periodical/newsletter
- 2. Other publications
- 3. Videos
- 4. Networking/matching with other families
- 5. National conferences
- 6. Referrals to local resources
- 7. National advecacy efforts
- 8. Fund research
- 9. Provide electronic computer bulletin board

Sibling Support Project

PO Box 5371, CL-09 Seattle, WA 98105-0371 (206) 368-4911 (voice) (206) 368-4816 (fax) 1.2.6.7

Creates materials and provides training and technical assistance for organizing peer-support and education programs for siblings of people with disabilities. Conducts workshops throughout the US for family members and service providers.

Travel

Mobility International USA

PO Box 10767 Eugene, OR 97440 (503) 343-1284 (V/TTY) (503) 343-6812 (fax) significancing (fax)

M miufa@igc.apc 1.2.3.4.6.7

Provides international educational, travel and leadership development opportunities for youths and adults with disabilities.
 Coordinates educational exchanges with other countries.
 Offers travel information and referral services for people with disabilities and their families.

Travel Information Service

Moss Rehab Hospital 1200 W Tabor Rd Philadelphia, PA 19141 (215) 456-9600 (voice) (215) 456-9602 (TTY) 6.7

• Provides free telephone information on travel accessibility to people with physical disabilities and their families.





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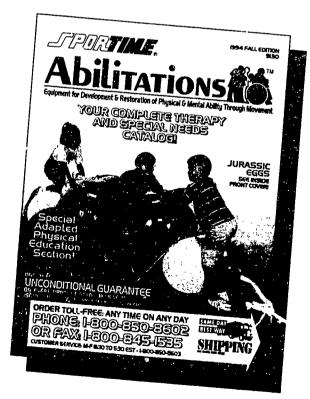
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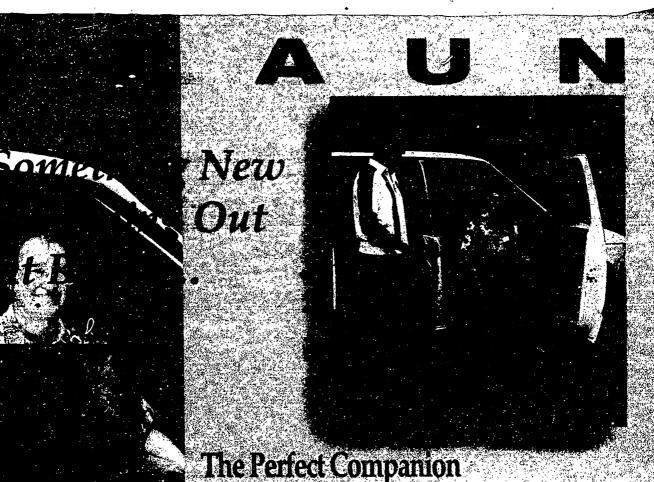
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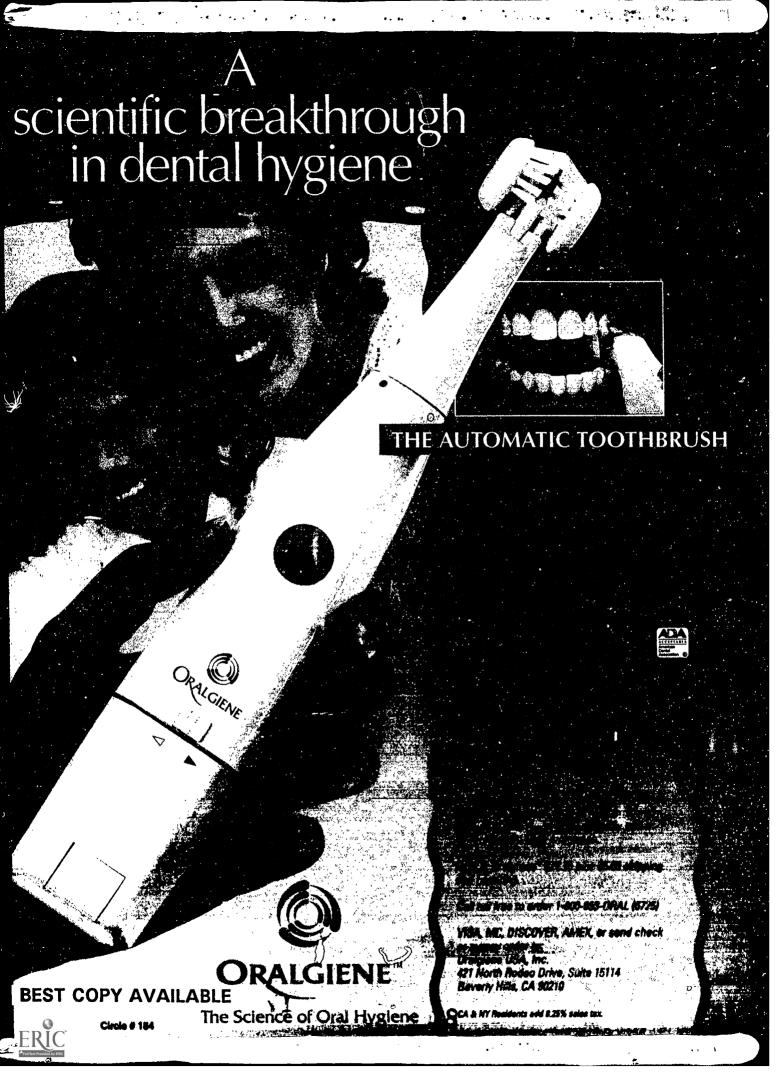


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National Resources for Specific Disabilities and Conditions

his directory includes national groups and organizations that can serve as resources for parents and professionals seeking information and support regarding specific disabilities and conditions. Where appropriate, disability categories have been cross-referenced to enable readers to find other relevant resources for a specific disability or condition. Where appropriate, several entries in this directory also appear in other directories within this volume.

A description of services provided by individual groups follows each listing. Numbers correspond to items listed in the Key to Services. This symbol () indicates an internet e-mail address. Unless otherwise indicated, telephone numbers are for voice only.

A-Beta-Lipoproteinemia

See: Tay-Sachs Disease

Aarskog Syndrome

See also: Growth Disorders

Aarskog Syndrome Parent Support Group

c/o Shannon Caranci 62 Robin Hill Ln Levittown, PA 19055-1411 (215) 943-7131 1,4,10

Acid Mattase Deficiency

See: Muscular Dystrophy

Acidemia, Organic

See also: Maple Syrup Urine Disease, Neurometabolic Disorders

Organic Acidemia Association

c/o Carol Barton 2287 Cypress Ave San Pablo, CA 94806 (510) 724-0297 1,4,5,10

Key to Services

- 1. Periodical/newsletter
- 2. Other publications
- 3. Videos
- 4. Networking/matching
- 5. Local chapters
- 6. National conferences
- 7. Referrals to local resources
- National advocacy efforts
- 9. Fund research
- Maintain registry of individuals with this condition
- 11. Electronic builetin board (BBS)

Acoustic Neuroma

See also: Balance Disorders & Dizziness, Hearing Impairments, Neurofibromatosis, Vestibular Disorders

Acoustic Neuroma Association

PO Box 12402 Atlanta, GA 30355 (404) 237-8023 (404) 237-2704 (fax) 1,2,3,4,5,6,10

Acoustic Neuroma Association of Canada

PO Box 369 Edmonton, AB CAN T5J 2J6 (800) 561-2622 (V/TTY, Canada) (403) 428-3384 (V/TTY) 1,2,3,4,5,6,7,8

Addison Disease

See: Adrenal Disorders; Adrenal Hyperplasia, Congenital

Adrena! Disorders

See also: Adrenal Hyperplasia, Congenital

National Adrenal Disease Foundation

505 Northern Blvd Great Neck, NY 11021 (516) 487-4992 1,2,4,5

Adrenai Hyperplasia, Congenitai

See also: Growth Disorders

Congenital Adrenai Hyperplasia Support Association

801 County Rd, #3 Wrenshall, MN 55797 (218) 384-3863 2,4,7,10

Adrenoleukodystrophy

See: Leukodystrophy

Adrenoleukodystrophy, Neonatal

See: Leukodystrophy

Agenesis of the Corpus Callosum

ACC Network

86 N Main St Orono, ME 04473 (207) 866-2062 (207) 581-3119 (207) 581-3120 (fax) 25 RHD351@maine.maine.edu 1,2,4,10

Agyria

See: Lissencephaly

Aicardi Syndrome

Aicardi Syndrome Awareness and Support Group

29 Delavan Ave Toronto, ON CAN M5P 1T2 (416) 481-4095

Aicardi Syndrome Newsletter

5115 Troy Urbana Rd Casstown, OH 45312 (513) 339-6033 (voice/fax) 1,2,4,6,7,8,10

AIDS

CDC National AIDS Hotline

American Society Health Assn PO Box 13827 Research Triangle Park, NC 27709 (800) 342-2437 (800) 344-7432 (Spanish) (800) 243-7889 (TTY)

National Pediatric HIV Resource Center

15 S 9th St Newark, NJ 07107 (800) 362-0071 (201) 268-8251 (201) 485-2752 (fax) 1,2,3,4,6,7,8,9; school nurse educational program

Alagille Syndrome

See also: Liver Disorders

Alagille Syndrome Alliance

10630 SW Garden Park-Pl Tigard, OR 97223 (503) 639-6217 1,4,10

Albinism & Hypopigmentation

See also: Visual Impairments

National Organization for Albinism and Hypopigmentation

1530 Locust St, #29 Philadelphia, PA 19102 (800) 473-2310 1,2,5,6,8

Alexander's Disease

See: Leukodystrophy

Allergy

See: Asthma & Allergy

Alopecia Areata

National Alopecia Areata Foundation

710 C St, Ste 11 San Rafael, CA 94901 (415) 456-4644 (415) 456-4274 (fax) 474301.1642@compuserve.com 1,2,3,4,5,6,7,8,9

Alstrom Syndrome

See also: Diabetes Mellitus, Hearing Impairments, Visual Impairments

Aistrom Syndrome Newsletter

1006 Howard Rd Warminster, PA 18974 1.10

Alternating Hemiplegia

See: Hemiplegia, Alternating

Amputation

See also: Limb Disorders

American Amputee Foundation

PO Box 250218 Little Rock, AR 72225 (501) 666-2523 (501) 666-8367 (fax) 1.2.3.5.7

National Amputation Foundation

73 Church St Malverne, NY 11565 (516) 887-3600 (516) 887-3667 (fax) 1.2.4.7

Anderson Disease

See: Glycogen Storage Disease

٠, ١

Anemia, Aplastic

Aplastic Anemia Foundation of America

PO Box 22689 Baltimore, MD 21203 (800) 747-2820 1,2,4,5,6,7,8,9,10

Anemia, Cooley's

See: Cooley's Anemia

Anemia, Fanconi

See also: Leukemia

Fanconi Anemia Research Fund/Support Group

1902 Jefferson, #2 Eugene, OR 97405 (503) 687-4658 (503) 687-0548 (fax) 1,2,4,5,6,8,9

Anemia, Hemolytic

See: Evans Syndrome

Angelman Syndrome

Angelman Syndrome Foundation

PO Box 12437 Gainesville, FL 32604 (904) 332-3303 1,3,4,6,9,10

Canadian Angelman Syndrome Society

PO Box 37 Priddis, AB CAN TOL 1WO (403) 931-2415 (voice/fax) 1,2,4,6,10; liaison with groups in other countries

Aniridia

See: Visual Impairments

Ankylosing Spondylitis, Juvenile

See: Arthritis

Anophthalmia

See: Visual Impairments

Anorectal Malformations

See also: Intestinal Pseudo-Obstruction Syndrome

Puli-Thru Network

1 Circle Rd Darien, CT 06820 (203) 655-6288 (201) 891-5932 1,4,10

Apert Syndrome

See also: Craniofacial Disorders

Apert Syndrome Pen Pai Network

PO Box 115 Providence, RI 02901 (401) 421-9076 4,7

Aphasia, Acquired

National Aphasia Association Young People's Network

PO Box 1887 Murray Hill Station New York, NY 10156-0611 (800) 922-4622 1.4.7

Aplastic Anemia

See: Anemia, Aplastic

Apraxia

See also: Language Disorders, Learning Disabilities

National Organization for Apraxia and Dyspraxia

30660 Milky Wy Dr, Ste I-66 Temecula, CA 92592 (909) 695-9446 1.2.4.7.10

Aqueductal Stenosis

See: Hydrocephalus

Arginase Deficiency
See: Urea Cycle Disorders

Argininosuccinic Aciduria

See: Urea Cycle Disorders

Arnold-Chlari Malformation
See also: Spina Bifida,
Syringomyelia

Arnold-Chiari Family Network

c/o Maureen & Kevin Walsh 67 Spring St Weymouth, MA 02188 (617) 337-2368 2.4

Arteriovenous Malformations (AVMs)

See: Vascular Malformations

Arthritis

American Juvenile Arthritis Organization

1314 Spring St NW
Atlanta, GA 30309
(800) 283-7800
(404) 872-7100
(404) 872-0457 (fax)

spharring@arthritis.org
1,2,3,4,5,6,7,8,9; partnership training program for parents and health care providers

Arthritis Society

250 Bloor St, Ste 901 Toronto, ON CAN M4W 3P2 (800) 361-1112 (Ontario only) (416) 967-1414 (416) 967-7171 (fax) 1,2,3,4,5,8,9

Arthrogryposis Multiplex Congenita

See also: Growth Disorders

AVENUES: A National Support Group for Arthrogryposis Multiplex Congenita

PO Box 5192 Sonora, CA 95370 (209) 928-3688 1,2,4,6,7,10

CAST: Canadian Arthrogryposis Support Team

365 Fiddler's Green Rd S Ancaster, ON CAN L9G 1X2 (209) 928-3688 1.3.4.5.7,10

Asperger Syndrome

See: Autism

Asthma & Allergy

See also: Lung Diseases

Allergy/Asthma Association

30 Eglinton Ave W, Ste 750 Mississauga, ON CAN L5R 3E7 (905) 712-2242 (905) 712-2245 (fax) 1,2,3,4,5,6,8

Asthma and Allergy Foundation of America

1125 15th St NW, Ste 502 Washington, DC 20005 (800) 727-8462 (202) 466-7643 (202) 466-8940 (fax) 1,5,7,8,9,10

Ataxia

National Ataxia Foundation

750 Twelve Oaks Ctr 15500 Wayzata Blvd Wayzata, MN 55391 (612) 473-7666 (612) 473-9289 (fax) 1,4,5,6,7,9

Ataxia Telangioctasia

See also: Autoi...mune Disorders, Immune Disorders

Ataxia Telangiectasia Children's Project

21646 Cartagena Dr Boca Raton, FL 33428 (407) 483-2661 1,4,5,6,7,8,9,10

Atresia

See: Microtia

Attention Deficit Disorder

See also: Learning Disabilities

Attention Deficit Disorder

AD-IN: Attention Deficit Information Network 475 Hillside Ave Needham, MA 02194 (617) 455-9895 2,3,7; scholarship program

Key to Services

- 1. Periodical/newsletter
- 2. Other publications
- 3. Videos
- 4. Networking/matching
- 5. Local chapters
- National conferences
- 7. Referrals to local resources
- 8. National advocacy efforts
- 9. Fund research
- 10. Maintain registry of individuals with this condition
- 11. Electronic bulletin board (BBS)

CHADD: Children and Adults with Attention Deficit Disorders

499 NW 70th Ave, Ste 109 Plantation, FL 33317 (800) 233-4050 (305) 587-3700 (305) 587-4599 (fax) 1,2,5,6

CHADD-Canada

PO Box 23007 Ottawa, ON CAN K2A 4E2 (613) 231-7646 (613) 231-7064 (fax) 1,2,5

Autism

See also: Language Disorders

Autism Research Institute 4182 Adams Ave San Diego, CA 92116 (619) 281-7165

1,2,3,7,10

Autism Society of America
7910 Woodmont Ave, Ste 650
Bethesda, MD 20814

(800) 328-8476 (301) 657-0881 (301) 657-0869 (fax) 1,2,4,5,6,7,8

Autism Society of Canada

129 Yorkville Ave, #202 Toronto, ON CAN M5R 1C4 (416) 922-0302 1.5.6.7.8

Center for Study of Autism

9725 SW Beaverton-Hillsdale Hwy, Ste 230 Beaverton, OR 97005 (503) 643-4121 4,5,6,7,8,9,10

More Advanced Autistic People

PO Box 524 Crown Point, IN 46307 1,2,6,8,10



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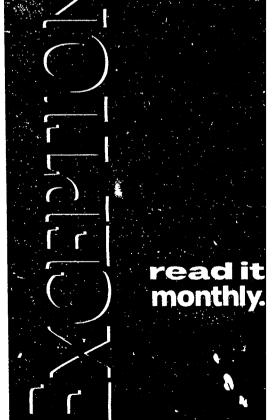
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National Autism Hotline/Autism Services Ctr

605 Ninth St Prichard Bldg PO Box 507 Huntington, WV 25710-0507 (304) 525-8014 (304) 525-8026 (fax) 1,3,4,7

Autism & Sensory impairments

See also: Hearing Impairments, Language Disorders; Visual Impairments

Autism and Sensory Impairments Network

c/o Dolores and Alan Bartel 7510 Oceanfront Ave Virginia Beach, VA 23451 (804) 428-9036 4,6,7,10

Autoimmune Disorders

See also: Immune Disorders

American Autoimmune Related Diseases Association

Michigan National Bank Bldg 15475 Gratiot Ave Detroit, MI 48205 (800) 598-4668 (313) 371-8600 (313) 371-6002 (fax) 1,2,5,7,8,9; physician seminars, public education

Balance Disorders & Dizziness

See also: Vestibular Disorders

EAR Foundation

2000 Church St, Box 111 Nashville, TN 37236 (800) 545-4327 (V/TTY) (615) 329-7807 1,2

Pen Pal Support Group for Chronic Dizziness & Balance Disorders

307 Second St Elliott, IA 51532 (712) 767-2325 1,4,7

Batten Disease

See also: Brain Diseases, Tay-Sachs Disease

Batten's Disease Support and Research Association

2600 Parsons Ave Columbus, OH 43207 (800) 448-4570 (614) 445-4161 1,3,4.5,6,7,9,10

BSB Syndrome

See. Opitz Syndrome

Beckwith-Wiedemann Syndrome

Beckwith-Wiedemann Support Network

3206 Braeburn Cir Ann Arbor, MI 48108 (800) 837-2976 (Parents only) (313) 973-0263 (313) 973-9721 (fax) 1,2,4,6,7,10

Bedwetting

See: Incontinence

Bereavement Support

Center for Loss in Multiple Birth

PO Box 1064 Palmer, AK 99645-1064 (907) 746-6123 1.4.7

Compassionate Friends

PO Box 3696 Oak Brook, IL 60522-3696 (708) 990-0010 (708) 990-0246 (fax) 1.2.3.5.6.7

Pen-Parents

PO Box 8738 Reno, NV 89507-8738 (702) 826-7332 1,2,4,6,7

Biliary Atresia

See: Liver Disorders

Biotinidase Deficiency

See: Neurometabolic Disorders

Birthmark

See: Nevi, Giant Congenital; Vascular Malformations

Bleeding Disorders

See: Hemophilia

Blepharophimosis

Blepharophimosis, Ptosis, Epicanthus Inversus Support Group

c/o Lynne Schauble SE 820 Meadow Vale Dr Pullman, WA 99163 (509) 332-6628 1,2,4,7,10

Blindness

See: Visual Impairments

Bloch-Siemens-Sulzberger Syndrome

See: Incontinentia Pigmenti

Blood Vessel Maiformation

See: Hemorrhagic Telangiectasis, Hereditary; Vascular Malformations

Bloom Syndrome

See: Growth Disorders

Brachmann-de Lange Syndrome

See: Cornelia de Lange Syndrome

Brain Diseases

Children's Brain Diseases Foundation

350 Parnassus Ave, Ste 900 San Francisco, CA 94117 (415) 565-6259 (415) 863-3452 (fax) 6.7,9

Brain Injury

International Brain Injury Association

1776 Massachusetts Ave NW, Ste 100 Washington, DC 20036-1904 (202) 296-6443 (202) 296-8850 (fax) 2,3,5,7,8

Brain Stem Maiformations

See: Amold-Chiari Malformation, Joubert Syndrome, Syringomyelia

Brain Tumors

See also: Brain Injury, Cancer, Epilepsy, Turcot Syndrome, Von Hippel-Lindau Syndrome

American Brain Tumor Association

2720 River Rd, Ste 146 Des Plaines, IL 60018 (800) 886-2282 (708) 827-9910 (708) 827-9918 (fax) 1.2.4.6.9

Brain Tumor Foundation of Canada

111 Waterloo St, Ste 600 London, ON CAN N6B 2M4 (519) 642-7755 (519) 642-7192 (fax) 1,2,4,6,7,8,9,10; quarterly "fun" days for children and families

Brain Tumor Society

60 Birmingham Pkwy Boston, MA 02135-1116 (617) 783-0340 (617) 783-9712 (fax) 1.2,4,6,8,9,10

Children's Brain Tumor Foundation

35 Alpine Ln Chappaqua, NY 10514 (914) 238-1656 (914) 238-6024 (fax) 1,2,7,8,9

National Brain Tumor Foundation

c/o Michael McKechnie 785 Market St, Ste 1600 San Francisco, CA 94102 (800) 934-2873 (415) 284-0208 (415) 284-0209 (tax) ★ sstf39b@prodigy.com 1,2,3,4,6,7,8,9

Burns

Phoenix Society for Burn Survivors

11 Rust Hill Rd Levittown, PA 19056 (800) 888-2876 (215) 946-2876 (215) 946-4788 (fax) 1,2,3,4,5,6,7,8,9

Canavan Disease

See: Leukodystrophy, Tay-Sachs Disease

Cancer

See also: Brain Tumors, Leukemia, Polyposis

American Cancer Society

1599 Clifton Rd NE Atlanta, GA 30329-4251 (800) 227-2345 1,3,4,5,6,7,8,9

Candlelighters Childhood Cancer Foundation

7910 Woodmont Ave, Ste 460 Bethesda, MD 20814 (800) 366-2223 (301) 718-2686 (fax) 12,5,6,7,8; advocacy program for insurance and second opinions

Candlelighters Childhood Cancer Foundation—Canada

10 Alcom Ave, Ste 200 Toronto, ON CAN M4V 3B1 (416) 926-1374 (416) 961-4189 (fax) 1,2,3,4,5,6,7,8; scholarship program, financial assistance program under development

Cancer, Brain

See: Brain Tumors, Turcot Syndrome

Cancer, Colon

See: Turcot Syndrome

Cancer, Gastrolatestinal

See: Peutz-Jeghers Syndrome, Polyposis

Carbannyi Phosphate Synthetase (CPS) Deficiency

See: Urea Cycle Disorders

Cardiac Disorders

See: Heart Disorders



A Circle of Help

The International Rett Syndrome Association gives parents a shoulder to lean on

Then Kathy Hunter was told, "You caused your daughter's condition," she refused to believe it. She began a 10-year search that would lead



Claudia Weisz and IRSA president Kathy Hunter oversee the IRSA booth at the World Congress on Neurology in September 1993.

her to a Viennese doctor and an answer—Rett syndrome, a genetic disorder occurring only in females and causing mental retardation, repetitive hand gestures and a loss of purposeful hand skills.

Rett syndrome had not been widely recognized by professionals and is still often misdiagnosed as autism or cerebral palsy. This confusion from people she perceived as being able to fix anything often frustrated Kathy. "We needed to know what was going on," she says.

In 1983, an article in the *Annals of Neurology* brought Rett syndrome—first identified in 1966 by

Dr. Andreas Rett—to the attention of the American medical community. Two years later, Stacie Hunter was diagnosed.

In the spring of 1985, Kathy founded the International Rett Syndrome Association (IRSA) with 16 other families. She wanted to make sure no other parents would be hurt by the public's lack of understanding. After 10 years of public awareness efforts, IRSA has greatly increased knowledge of the syndrome. More than \$12 million has been awarded to researchers in the past decade; many feel they are within a few years of identifying the syndrome's cause and, perhaps, an effective treatment.

IRSA's major role, however, is as a support for parents. "It is a powerful, comforting force to know that you can pick up a telephone and know there's someone on the other end who knows what you're going through when your kid won't sleep nights," Kathy said. Local groups provide contacts and emotional support for families. Seminars and meetings keep parents up-to-date on the latest in research and care for a child with Rett syndrome. Benefits like a night of "Beer, Beef and Bowling" help fund the organization and provide entertainment for families. Professionals attend many of these events with parents, and often come away imbued with the passion parents feel.

Kathy Hunter is proud of the organization that started around her kitchen table. "It's liberating to know that you're not alone," she says, adding that, as president, "I don't consider it a job; I consider it a privilege."

-Jennifer M. noerber

Key to Services

- 1. Periodical/newsletter
- 2. Other publications
- 3. Videos
- 4. Networking/matching
- 5. Local chapters
- 6. National conferences
- 7. Referrals to local resources
- 8. National advocacy efforts
- 9. Fund research
- Maintain registry of individuals with this condition
- 11. Electronic bulletin board (BBS)

Cardio-Facio-Cutaneous Syndrome

See also: Noonan Syndrome

CFC Support Network

157 Alder Ave McKee City, NJ 08232 (609) 646-5606 1.4.10

Carnitine Deficiency

See: Acidemia, Organic; Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD); Muscular Dystrophy

Carnitine Paimityitransferase Deficiency

See: Acidemia, Organic; Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCAD); Muscular Dystrophy

Cartilage-Hair Hypopiasia

See: Growth Disorders, Schwachman Syndrome

Caudal Syndrome

See: Growth Disorders

Celiac Disease

See also: Celiac Sprue, Gluten Intolerance

Celiac Disease Foundation

13251 Ventura Blvd, #3 Studio City, CA 91604-0265 (818) 990-2354 (818) 990-2379 (fax) 1,2,4,5 7.8,10

Cellac Sprue

See also: Celiac Disease, Gluten Intolerance

American Celiac Society

58 Musano Ct West Orange, NJ 07052 (201) 325-8837 Abentleac@umdnj.edu

1,4,5,6,7,8,9



Celiac Sprue Association

P0 Box 31700 Omaha, NE 68131-0700 (402) 558-0600 (402) 558-1347 (fax) 1.2,3,4,5,6,7,9

Central Core Disease

See: Muscular Dystrophy

Central Hypoventilation Syndrome, Congenital

See also: Intestinal Pseudo-Obstruction Syndrome, Ventilator Use

Congenital Central Hypoventilation Syndrome Parent Network

71 Maple St Oneonta, NY 13820 1,4,6,10

Centronuclear Myopathy

See: Myotubular Myopathy

Cerebellar Vermis Aplasia/Hypoplasia

See: Joubert Syndrome

Cerebral Palsy

United Cerebral Palsy Associations

1522 K St NW, #1112 Washington, DC 20005 (800) 872-5827 (202) 842-1266 (V/TTY) (202) 842-3519 (fax) valuepainc@aol.com 1,2,3,5,6,7,8,9; therapy

1,2,3,5,6,7,8,9; therapy programs; information about technology, recreation, early intervention and employment

Cerebrotendinous Xanthomatosis

See: Leukodystrophy, Tay-Sachs Disease

Chanarin-Dorfman Syndrome

See: Ichthyosis

Charcot-Marie-Tooth Disease

See also: Ataxia, Muscular Dystrophy, Myelin Disorders

Charcot-Marie-Tooth Association

601 Upland Ave Upland, PA 19015 (800) 606-2682 (215) 499-7486 (215) 499-7429 (fax) 1,2,3,5,7,9,10, regional conferences, physician's handbook

Charcot-Marie-Tooth International

1 Springbank Dr St Catharines, ON CAN L2S 2K1 (905) 687-3630 (905) 687-8753 (fax) 1.2.4.7.10

CHARGE Syndrome

CHARGE Syndrome Foundation

2004 Parkade Blvd Columbia, M0 65202-3121 (800) 442-7604 mnorbury@bigcat.missouri.edu 1,2,4,6,7,10

Chiari Malformation

See: Arnold-Chiari Malformation

CHILD Syndrome

See: Ichthyosis

Cholesteryl Ester Storage Disease

See: Tay-Sachs Disease

Chondrodysplasia Punctata

See: Growth Disorders, Ichthyosis

Choroideremia

See: Macular Diseases, Retinitis Pigmentosa, Visual Impairments

Chromosome 4p-

See: Wolf-Hirschhorn Syndrome

Chromosome 5p-

See: Cri Du Chat Syndrome

Chromosome 6 Disorders

Spotlight 6

c/o Valerie Wiggins 56 Edmundson Ln Rising Sun, MD 21911 1,4,10

Chromosome 9 @/sorders

Support Group for 9p-

c/o Beverly Udell 675 N Round Table Dr Las Vegas, NV 89110 (702) 453-0788 1,2,3,4,7,10

Support Group for Monosomy 9p

43304 Kipton Nickle Plate Rd La Grange, OH 44050 (216) 775-4255 1,4,10; bibliography, Japanese and French translations

Trisomy 9 International Parent Support

Children's Hospital of Michigan 3901 Beaubien Blvd Detroit, MI 48201-2196 (313) 745-4513 (313) 745-4827 (fax) 1,4,7,10

Chromosome 15 Disorders

IDEA: Inverted Duplication Exchange & Advocacy

c/o Donna Bennett RD #1, Box 260B Thomasville, PA 17364-9768 (717) 225-5229 (610) 891-2313 1.4.10

Chromosome 17p-

See: Smith-Magenis Syndrome

Chromosome 18 & 13 Disorders

Chromosome 18 Registry & Research Society

6302 Fox Head San Antonio, TX 78247 (210) 657 4968 (voice/fax) 1,4,6,10

SOFT: Support Organization for Trisomy 18, 13 and Related Disorders

c/o Barb Van Herreweghe 2982 S Union St Rochester, NY 14624 (716) 594-4621 (voice/fax) 1,2,4,5,6,7,10

SOFT—Canada: Support Organization for Trisomy 18, 13 and Related Disorders

760 Brant St, Ste 420 Burlington, ON CAN L7R 4B8 (800) 668-0898 (Canada only) (905) 632-7755 (905) 632-5997 (fax) 1.2.4.6.10

Chromosome 22 Disorders

See: DiGeorge Syndrome, Velo-Cardio-Facial Syndrome

Chromosome 45,X0

See: Turner Syndrome

Chromosome 45,X0/46,XX

See: Turner Syndrome

Chromosome 47,XXY

See: Klinefelter Syndrome

Chromosome 48,XXXY

See: Klinefelter Syndrome

Chromosome 49,XXXXY

See: Klinefelter Syndrome

Chromosome Deletions

Chromosome Deletion Outreach

Box 280 Driggs, ID 83422 (208) 354-8550 1,4,7,10; also deals with chromosome additions, inversions and translocations

Chromosome Inversions

National Center on Chromosome Inversions

1029 Johnson St Des Moines, IA 50315 (515) 287-6798 (voice/fax) 4.7.8.10

Citruliinemia

See: Urea Cycle Disorders

Cleft Palate

See also: Craniofacial Disorders

Cleft Palate Foundation

1218 Grandview Ave Pittsburgh, PA 15211 (800) 242-5338 (412) 481-1376 (412) 481-0847 (fax) 2,4,6,7,9

Cockayne Syndrome

See also: Growth Disorders, Progeria, Xeroderma Pigmentosum

Share and Care Cockayne Syngrome Network

c/o Theresa Wall PO Box 552 Stanleytown, VA 24168 (703) 629-2369 (703) 647-3739 (fax)

Coffin-Lowry Syndrome

Coffin-Lowry Syndrome Foundation

PO Box 10003 Bainbridge Island, WA 98110 (206) 842-1523 1,2,4,10

Coffin-Sirius Syndrome

See: Coffin-Lowry Syndrome

Colitis

See: Crohn's Disease & Colitis

Coloboma

See: Visual Impairments

Conradi-Hünermann Syndrome

See: Growth Disorders, !chthyosis

Cooley's Anemia

Cooley's Anemia Foundation

12909 26th Ave Flushing, NY 11354 (800) 552-7222 (718) 321-2873 (718) 321-3340 (fax) 1,2,3,4,5,6,7,8,9,10; financial assistance, fellowships

Cornella de Lange Syndrome

Cornelia de Lange Syndrome Foundation

60 Dyer Ave Collinsville, CT 06022-1273 (800) 223-8355 (800) 753-2357 (203) 693-0159 (203) 693-6819 (fax) 1,2,3,4,6,10: professional network



Corpus Callosum, Disorders of

See: Agenesis of the Corpus Callosum

Craniocarpotarsal Dystrophy

See: Freeman-Sheldon Syndrome

Craniofaciai Disorders

See also: Apert Syndrome, Cleft Palate, Crouzon's Disease, Freeman-Sheldon Syndrome, Goldenhar Syndrome, Holoprosencephaly, Microtia, Moebius Syndrome, Nager & Miller Syndromes, Treacher Collins Syndrome

AboutFace-Canada

99 Crowns Ln, 3rd Floor Toronto, ON CAN M5R 3P4 (800) 665-3223 (416) 944-3223 (416) 944-2488 (fax) 1,2,3,4,5,6,7; program to teach school children about facial differences, outreach program to families with newborns

AboutFace-USA PO Box 737

Children's Craniofacial Association

10210 N Central Expressway Ste 230, LB37 Dallas, TX 75231 (800) 535-3643 (214) 994-9902 (214) 994-9831 (fax) 1,2,4,6,7,10

Craniofacial Foundation of America

c/o Terri Farmer 975 E Third St Chattanooga, TN 37403 (615) 778-9192 1,2,4,5 7,10; financial assistance for non-medical expenses

FACES—National Association for the Craniofacially Handicapped

PO Box 11082 Chattanooga, TN 37401 (800) 332-2373 (615) 267-3124 (fax) 1,4,7,8,10

Forward Face

317 34th St, 9th Fl
New York, NY 10016
(800) 422-3223
(212) 263-5205
(212) 263-7534 (fax)
1,3,4,7; apartment in NYC for families of children undergoing treatment, adolescent support group, assistance with transportation costs, scholarships

Inst of Reconstructive Plastic Surgery

Let's Face It

PO Box 711 Concord, MA 01742 (508) 371-3186 1,4,7,8; annual resource guide

National Foundation for Facial Reconstruction

317 E 34th St, Rm 901 New York, NY 10016 (800) 422-3223 (212) 263-6656 (212) 263-7534 (fax) 1.4.6.7.8.9.10

Craniosynostosis

See: Craniofacial Disorders

Cri Du Chat Syndrome

5p-Society 11609 Oakmont Overland Park, KS 66210 (913) 469-8900 1,2,4,6,7,8,9,10

Crohn's Disease & Colitis

CCFA: Crohn's & Colitis Foundation of America

386 Park Ave S, 17th Floor New York, NY 10016-8804 (800) 932-2423 (212) 685-3440 (212) 779-4098 (fax) 1.5.7.9

Pediatric Crohn's & Colitis Association

Box 188 Newton, MA 02168 (617) 290-0902 1.2.4.7

Crouzon's Disease

See also: Craniofacial Disorders, Hearing Impairments

Crouzon's/Meniere's Parent Support Network

c/o Kathleen Handsaker PO Box 12791 Prescott, AZ 86304-2791 (602) 445 1743 (After March I., 1995, 602 area code changes to 520) 4.7

Cushing Syndrome

See: Adrenal Disorders; Adrenal Hyperplasia, Congenital

Cyclic Vomiting Syndrome

Cyclic Vomiting Syndrome Association 13180 Caroline Ct

(414) 784-6842 (414) 821-5494 (fax) ** Kadams@post.its.mcw.edu 1,2,3,4,5,6,7,9,10

Cystic Fibrosis

Flm Grove WI 53122

Canadian Cystic Fibrosis Foundation

2221 Yonge St, Ste 601 Toronto, ON CAN M4S 2B4 (800) 378-2233 (Canada only) (416) 485-9149 (416) 485-0960 (fax) 1,2,3,5,6,7,8,9,10

Cystic Fibrosis Foundation

6931 Arlington Rd Bethesda, MD 20814 (800) 344-4823 (301) 951-4422 (301) 951-6378 (fax) 1,2,3,5,6,7,8,9,10

Cystinosis

See also: Kidney Disorders

Cystinosis Foundation

1212 Broadway, Ste 830 Oakland, CA 94612 (800) 392-8458 1,4,6,7,8,9,10

Cystinuria

See also: Kidney Disorders

Cystinuria Support Network

22814 NE 21st PI Redmond, WA 98053 (206) 868-2996 24 75512.3161@compuserve.com 1,4,10

Cytomogalovirus (CMV), Congenital

National CMV Registry

c/o Gail Demmler, MD
Texas Children's Hospital
Clinical Care Center, Ste 1150
6621 Fannin St, MC 3-2371
Houston, TX 77030-2399
(713) 770-4330
(713) 770-4347 (fax)
1,4,7

Darier Disease

See: Ichthyosis

Deaf-Blind

See also: Hearing Impairments, Visual Impairments

American Association of the Deaf-Blind

814 Thayer Ave, Ste 302 Silver Spring, MD 20910 (301) 588-6545 (TTY only) (301) 588-8705 (fax) 1,4,6,7,8

27

Key to Services

- 1. Periodical/newsletter
- 2. Other publications
- 3. Videos
- 4. Networking/matching
- 5. Local chapters
- 6. National conferences
- 7. Referrals to local resources
- 8. National advocacy efforts
- 9. Fund research
- Maintain registry of individuals with this condition
- 11. Electronic bulletin board (BBS)

DB-LINK: National Information Clearinghouse on Children Who are Deaf-Blind

345 N Monmouth Ave Monmouth, OR 97361 (800) 438-9376 (800) 854-7013 (TTY) 24 Leslie@fsa.wosc.osshe.edu

National Family Association for the Deaf-Blind

111 Middle Neck Rd Sands Point, NY 11050 (800) 255-0411 (V/TTY) (516) 944-8900 (voice) (516) 944-8637 (TTY) 1,4,5,7,8

Deafness

See: Hearing Impairments

Debrancher Enzyme Deficiency

See: Muscular Dystrophy

Dejerine Sottas Disease

See: Muscular Dystrophy

Dermatitis Herpetiformis

See: Celiac Disease, Celiac Sprus, Gluten Intolerance

Dermatomyositis

See: Arthritis, Muscular Dystrophy, Myositis

Diabetes insipidus

Diahetes Insipidus and Related Disorders Network c/o Beth Perry

C/o Beth Perry Rt 2, Box 198 Creston, IA 50801 (515) 782-7838 1,4

Diabetes Mellitus

American Diabetes Association

National Service Ctr 1660 Duke St Alexandria, VA 22314 (800) 232-3472 (703) 549-1500 (703) 683-2890 (fax) 1.2,3,5,6,7,9,10



Canadian Diabetes Association

15 Toronto St, Ste 1001 Toronto, ON CAN M5C 2E3 (416) 363-3373 (416) 363-3393 (fax) 1.5.8.9

Juvenile Diabetes Foundation—Canada

89 Granton Dr Richmond Hill, ON CAN L4B 2N5 (800) 668-0274 (Canada only) (905) 889-4171 (905) 889-4209 (fax) 1,3,5,6,8,9

Juvenile Diabetes Foundation International

432 Park Ave S, 16th Fl New York, NY 10016 (800) 533-2873 (212) 889-7575 (212) 532-8791 (fax) 25 jBROCH@jdf.usa.com 1,2,5,9

DiGeorge Syndrome

See also: Immune Disorders, Velo-Cardio-Facial Syndrome

Information and Support for DiGeorge and Shprintzen Syndrome Families

c/o Natalie Ward 27859 Lassen St Castaic, CA 91384 (805) 294-3623 1,4,7,10

Digestive Disorders

See: Celiac Disease, Celiac Sprue, Crohn's Disease & Colitis, Gluten Intolerance, Ostomy

Dimorsier Syndrome

See: Growth Disorders

Down Syndrome

Association for Children with Down Syndrome

2616 Martin Ave Bellmore, NY 11710 (516) 221-4700 (516) 221-4311 (fax) 1,2,3,7,9

Canadian Down Syndrome Society

12837 76th Ave, Ste 206 Surrey, BC CAN V3W 2V3 (604) 599-6009 (604) 599-6165 (fax) 1,2,3,4,5,6,7

International Foundation for Genetic Research

400 Penn Center Blvd, Ste 721 Pittsburgh, PA 15235 (412) 823-6380 (412) 829-7304 (fax) 1,8,9; anti-abortion advocacy

National Down Syndrome Congress

1605 Chantilly Dr, Ste 250 Atlanta, GA 30324 (800) 232-6372 (404) 633-1555 (404) 633-2917 (fax) 1,4,6,7,8,10

National Down Syndrome Society

666 Broadway, 8th FI New York, NY 10012-2317 (800) 221-4602 (212) 460-9330 (212) 979-2873 (fax) 1,2,3,5,6,7,8,9,10

Dubowitz Syndrome

See: Growth Disorders

Dwarfism

See also: Growth Disorders, Short Stature

Billy Barty Foundation

929 W Olive Ave, Ste C Burbank, CA 91506 (818) 953-5410 (818) 953-7129 (fax) 1,2,3,7,8; emergency financial assistance, scholarships

Dysautonomia, Familial

Dysautonomia Foundation

20 E 46th St, Rm 302 New York, NY 10017 (212) 949-6644 (212) 682-7625 (fax) 1,2.5,6,10; treatment center

Dyslexia

See also: Attention Deficit Disorder, Language Disorders, Learning Disabilities

Dyslexia Research Institute

4745 Centerville Rd Tallahassee, FL 32308 (904) 893-2216 (904) 893-2440 (fax) 1,2,7,8

Orton Dyslexia Society

Chester Bldg, Ste 382 8600 La Salle Rd Baltirnore, MD 21286-2044 (800) 222-3123 (410) 296-0232 (410) 321-5069 (fax) 1,2,5,6,7,9

18

Dyspraxla

See: Apraxia

Dystonia

Dystonia Medical Research Foundation One E Wacker Dr. Ste 2900

Dystrophic Epidermolysis Builosa

DEBRA: Dystrophic Epidermolysis Bullosa Research Association

40 Rector St New York, NY 10006 (212) 693-6610 1,2,3,4,5,6,7,8,9,10

Ear Anomalies

See: Craniofacial Disorders, Microtia

Ectodermai Dyspiasia

National Foundation for Ectodermal Dysplasias

219 E Main, PO Box 114 Mascoutah, IL 62258-0;14 (618) 566-2020 (618) 566-4718 (fax) 1,2,3,4,5,6,7,8,9,10

Ehlers-Danios Syndrome

Ehiers-Danios National Foundation

PO Box 1212 Southgate, MI 48195 (313) 282-0180 (313) 282-2793 (fax) 1,2,3,4,5,6,7,9,10

Encephalitis, Chronic with Seizures

See: Rasmussen Syndrome

Epicanthus Inversus

See: Blepharophimosis

Epidermolysis Bullosa

See: Dystrophic Epidermolysis Bullosa

Epidermolytic Hyperkeratosis

See: Ichthyosis

Epilepsy

See also: Seizure Disorders

Security - Fall-man Basis

American Epilepsy Society 638 Prospect Ave Hartford, CT 06105-4298 (203) 586-7505 (203) 586-7550 (fax) 1,2

Epilepsy Canada

1470 Peel St, Ste 745 Montreal, PQ CAN H3A 1T1 (514) 845-7855 (514) 845-7866 (fax) 1,5,7,9

Epilepsy Foundation of America

4351 Garden City Dr Landover, MD 20785-2267 (800) 332-1000 (800) 332-2070 (TTY) (301) 459-3700 (301) 577-4941 (fax) 1,4,5,6,7,8,9; employment services, library

Erythrokeratodermias

See: Ichthyosis

Esophageal Atresia

See: VATER Association

Essential Tremor

See: Tremor

Evans Syndrome

See also: Autoimmune Disorders

Evans Syndrome Support and Research Group

Feed of the control o

Extracorporeal Membrane Oxygenation

ECMO Moms and Dads International Parent Support

P0 Box 53848 Lubbock, TX 79453 (806) 794-0259 1,2,4,5,6,7,10

Fabry Disease

See: Tay-Sachs Disease

Facial Disfigurement

See: Craniofacial Disorders

Facio-Scapulo-Humeral Muscular Dystrophy

See also: Muscular Dystrophy

Facio-Scapulo-Humeral Society

3 Westwood Rd Lexington, MA 02173 (617) 860-0501 1,4,5,6,7,8,9

Fanconi Anemia

See: Anemia, Fanconi

ERIC

Fetal Alcohol Syndrome/Effect

Family Empowerment Network: Support for Families Affected by FAS/FAE

619 Langdon St, Rm 521 Madison, WI 53703 (800) 462-5254 (608) 262-6590 (608) 265-2329 (fax) 1,2,4,6,7; lending library

Fetal Alcohol Education Program

7 Kent St Brookline, MA 02146 (617) 739-1424 (617) 566-4019 2.7

Fetal Alcohol Network

158 Rosemont Ave Coatesville, PA 19320-3727 2 72157.564@compuserve.com

National Organization on Fetal Alcohol Syndrome

1815 H St NW, Ste 710 Washington, DC 20006 (202) 785-4585 (202) 466-6456 (fax) 1,2,3,6,7

The Fetal Alcohol Syndrome Family Resource Institute

PO Box 2525 Lynnwood, WA 98036 (206) 778-4048 1,2,4,7,8,10; crisis-intervention line, teen prevention program for high schools

Fibrodysplasis Ossificans Progressiva

International Fibrodysplasis Ossificans Progressiva Association

910 N Jericho Dr Casselberry, FL 32707 (407) 365-4194 (voice/ťax) 1,2,3,4,6,9,10

Fibromyalgia See: Arthritis

Fibular Hemimella

See: Limb Disorders

Forbes Disease

See: Glycogen Storage Disease

Fragilia X Syndrome

See also: Attention Deficit Disorder, Autism, Learning Disabilities

FraXa Research Foundation

PO Box 935 West Newbury, MA 01985 (508) 462-1990 fraxa@destek.net 1,2,4.5,8,9,10 National Fragile X Foundation

1441 York St, Ste 215 Denver, CO 80206 (800) 688-8765 (303) 333-6155 (303) 333-4369 (fax) 1,2,3,4,7,10

Freeman-Sheldon Syndrome

See also: Craniofacial Disorders

Freeman-Sheidon Parent Support Group

509 E Northmont Wy Salt Lake City, UT 84103 (801) 364-7060 1,2,4,7,10

Friedreich's Ataxia

See: Muscular Dystrophy

Fucosidosis

See: Tay-Sachs Disease

G Syndrome

See: Opitz Syndrome

Galactosomia

See also: Neurometabolic Disorders

Parents of Galactosemic Children

2871 Stagecoach Dr Valley Springs, CA 95252 (209) 772-2449 (voice/fax) 1,4,5,6,9,10

Gaucher Disease

See also: Tay-Sachs Disease

National Gaucher Foundation 11140 Rockville Pike, Ste 350

Rockville, MD 20852-3106 (800) 925-8885 (301) 816-1515 (301) 816-1516 (fax) 1,2,5,6,7,9

Giroux-Barbeau Syndrome

See: Ichthyosis

Giaucoma

Glaucoma Research Foundation

490 Post St, Ste 830 San Francisco, CA 94102 (800) 826-6693 (415) 986-3162 (415) 986-3763 (fax) 1,2,4,7,9

Giutaricaciduria il

See: Acidemia, Organic

Gluten Intolerance

See also: Celiac Disease, Celiac Sprue

Gluten Intolerance Groups of North America

PO Box 23053 Seattle, WA 98102-0353 (206) 325-6980 (206) 850-2394 (fax) 1,2,3,4,6,7,8,9,10 Glycogen Storage Disease

See also: Hypoglycemia

Association for Glycogen Storage Disease

PO Box 896 Durant, IA 52747 (319) 785-6038 (voice/fax) 1.6.9.10

Glycosphingolipidoses

See also: Tay-Sachs Disease

Goldenhar Syndrome

See also: Craniofacial Disorders

Goldenhar Syndrome Research & Information Fund

8829 Gleneagles Ln Darien, IL 60561 (708) 910-3939 (708) 910-4065 (fax) 4,7,9,10

Granulomatous Disease, Chronic

See also: Autoimmune Disorders, Wegener Granulomatosis

Chronic Granulomatous Disease Association

c/o Mary Hurley 2616 Monterey Rd San Marino, CA 91108 (818) 441-4118 1,4,7,9,10

Graves Disease

See also: Thyroid Disorders

National Graves Disease Foundation

320 Arlington Rd Jacksonville, FL 32211 (904) 724-0770 (voice/fax) 1,2,3,4,5,6,7

Group B Strep

Canadian Group B Strep Association

c/o Donna Vlicny 343 Watson Ave Windsor, ON CAN N8S 3S3 (519) 948-6324 4.7; information packets for health care professionals

Group B Strep Association

PO Box 16515 Chapel Hill, NC 27516 (919) 932-5344 (voice/fax) 1,2,4,6,7,8,10

Growth Disorders

See also: Dwarfism, Short Stature

Human Growth Foundation 7777 Leesburg Pike

Falls Church, VA 22043 (800) 451-6434 (703) 883-1773 (703) 883-1776 (fax) 1,2,3,4,5,6,7,9,10

£ 4,

Key to Services

1. Periodical/newsletter

2. Other publications

3. Videos

4. Networking/matching

5. Local chapters

6. National conferences

7. Referrals to local resources

8. National advocacy efforts

9. Fund research

10. Maintain registry of individuals with this condition

11. Electronic bulletin board (BBS)

Little People's Research Fund

80 Sister Pierre Dr Towson, MD 21204 (800) 232-5773 (410) 494-0055 (410) 494-0060 (fax) 1,3,4,5,7,9,10

MAGIC Foundation for Children's Growth

1327 N Harlem Ave Oak Park, IL 60302 (800) 362-4423 (708) 382 0808 (708) 383-0899 (fax) 1,2,3,4,5,6,7,10

Growth Hormone Deficiency

See: Growth Disorders

Growth Retardation, intrauterine

See: Growth Disorders

Hailey-Hailey Disease

See: Ichthyosis

Hallerman-Strefff Syndrome See: Craniofacial Disorders, Short

See: Craniofacial Disorders, Short Stature

Hand-Shoulder Syndrome

See: Reflex Sympathetic Dystrophy Syndrome

Harlequin ichthyosis
See: Ichthyosis

Head injuries

National Head Injury Foundation

1776 Massachusetts Ave NW, Ste 100 Washington, DC 20036-1904 (800) 444-6443 (helpline) (202) 296-6443 (202) 296-8850 (fax) 1.2.3.5.6.7.8

Hearing Impairments

Alexander Graham Bell Association for the Deaf 3417 Volta PI NW

Washington, DC 20007-2778 (202) 337-5220 (V/TTY) 1,2,3,4,5,6,7,8,9,10



American Society for Deaf Children

2848 Arden Wy, Ste 210
Sacramento, CA 95825-1373
(800) 942-2732 (V/TTY)
(916) 482-0121 (fax)
1,4,5,6,7,8; "First-Year-Free"
Program for families of newly diagnosed children

Auditory-Verbal International

2121 Eisenhower, Ste 402 Alexandria, VA 22314 (703) 739-1049 (703) 739-0874 (TTY) (703) 739-0395 (fax) 1,4,6

Better Hearing Institute

PO Box 1840 Washington, DC 20013 (800) 327-9355 (V/TTY) (703) 750-9302 (fax) 1.2.3.7

Canadian Hard of Hearing Association

2435 Holly Ln, Ste 205 Ottawa, ON CAN K1V 7P2 (800) 263-8068 (Canada only) (613) 526-1584 (613) 526-2692 (TTY) (613) 526-4718 (fax) 1,5,6,7,8; publications in French and English

Canadian Hearing Society

271 Spadina Rd
Torento, ON CAN M5R 2V3
(416) 964-9595
(416) 964-0023 (TTY)
(416) 964-2066 (fax)

☑ chs-ho@chs.onramp.ca
1,2,3,5,6,7,8

Cochlear implant Club International

PO Box 464
Buffalo, NY 14223
(716) 838-4662 (V/TTY)
23 76207.3114@compuserve.com
1.4.5.6.7.8

HEAR Now

9745 E Hampden Ave, Ste 300 Denver, CO 80231-4923 (800) 648-4327 (V/TTY) (303) 695-7797 (V/TTY) (303) 695-7789 (fax) 1,9; financial assistance for hearing aids and cochlear implants

John Tracy Clinic

806 W Adams Blvd Los Angeles, CA 90007 (800) 522-4582 (V/TTY) (213) 748-5481 (213) 747-2924 (TTY) (213) 749-1651 (fax) 1,7,8; free correspondence course for pre-schoolers

National Association of the Deaf

814 Thayer Ave Silver Spring, MD 20910-4500 (301) 587-1788 (301) 587-1789 (TTY) (301) 587-1791 (fax) 1,2,5,6,7,8

National Cued Speech Association

PO Box 31345
Raleigh, NC 27622
(919) 828-1218 (V/TTY)
(919) 828-1862 (fax)
Sincsa@aol.com
1,2,3,4,5,6,7,8,10,11

NIDCD Hereditary Hearing Impairment Resource Registry

Boys Town National Research
Hospital
55 N 30th St
Omaha, NE 68131
(800) 320-1171 (V/TTY)
(402) 498-6331 (fax)
deaf@boystown.org
1.2.7.10

Self-Help for Hard of Hearing People

7910 Woodmont Ave, Ste 1200 Bethesda, MD 20814 (301) 657-2248 (301) 657-2249 (TTY) (301) 913-9413 (fax) 1,4,5,6,7,8

Signing Exact English (SEE) Center for the Advancement of Deaf Children

PO Box 1181 Los Alamitos, CA 90720 (310) 430-1467 (V/TTY) (310) 795-6614 (fax) 3,7,9

Telecommunications for the Deaf, Inc

8719 Colesville Rd, Ste 300 Silver Spring, MD 20910 (301) 589-3786 (301) 589-3006 (TTY) (301) 589-3797 (fax) 24 zztdias@gallua.gallaudet.edu 1,2,3,6,7,8

TRIPOD Grapevine

2901 N Keystone St Burbank, CA 91504 (800) 352-8888 (V/TTY) (800) 287-4763 (V/TTY, CA only) 3,4,7

VOICE for Hearing-Impaired Children

124 Eglinton Ave W. Ste 420 Toronto, ON CAN M4R 2G8 (416) 487-7719 (V/TTY) (410) 487-7423 (fax) 1,4,5,7,8

Heart Disorders

American Heart Association

7272 Greenville Ave Dallas, TX 75231-4596 (800) 242-8721 (214) 373-6300 (214) 369-3685 (fax) 1,2,3,7,8,9

CHASER: Congenital Heart Anomalies—Support, Education & Resources

2112 N Wilkins Rd Swanton, OH 43558 (419) 825-5575 (419) 825-2880 (fax) 54 75050.2742@compuserve.com 1,4,7,8,10

Hemangioma

See also: Vascular Malformations

Hemangioma Hope

c/o Cindy Dougan 8400 Rohl Rd North East, PA 16428 (814) 898-1054 1,2,3,4,6,10

Hemidysplasia, Unitateral

See: Ichthyosis

Hemifacial Microsomia

See: Goldenhar Syndrome

Hemihypertrophy

See: Beckwith-Wiedemann Syndrome

Hemiplegia, Alternating

See also: Epilepsy, Seizure Disorders

International Foundation for Alternating Hemiplegia of Children

29 Leonard Rd Melrose, MA 02176 (617) 665-8906 4,9,10

Hemoivtic Anemia

See: Evans Syndrome

Hemophilia

Canadian Hemophilia Society

1450 City Councillors, Ste 840 Montreal, PQ CAN H3A 2E6 (800) 668-2686 (Canada only) (514) 848-0503, ext 24 (514) 848-9661 (fax) 1,2,3,4,5,6,7,8,9

National Hemophilia Foundation

110 Greene St, Rm 303 New York, NY 10012 (212) 219-8180 (212) 966-9247 (fax) 1,2,3,4,5,6,7,8,9,10

Hemorrhagic Telanglectasis, Hereditary

See also: Anemia, Aplastic; Vascular Malformations

HHT Foundation International PO Box 8087

New Haven, CT 06530 (800) 448-6389 (US only) (313) 561-2537 (US) (313) 561-4585 (US, fax) (604) 596-3418 (Canada) (604) 596-0138 (Canada, fax) 1,2,4,6,10; pen-pal group

Hermansky-Pudiak Syndrome

See also: Albinism & Hypopigmentation, Visual Impairments

Hermansky-Pudlak Syndrome Network

39 Riveria Ct Malverne, NY 11565-1602 (800) 789-9477 (516) 599-2077 2,4,8,9,10

Hers Disease

See: Glycogen Storage Disease

Hirschsprung Disease

See: Intestinal Pseudo-Obstruction Syndrome

Histiocytosis

See also: Diabetes Insipidus, Growth Disorders

Histiocytosis Association of America

609 New York Rd Glassboro, NJ 08028 (800) 548-2758 (609) 589-6614 (fax) 1,2,4,7,9,10; financial support

Holoprosencephaly

See also: Craniofacial Disorders

Holoprosencephaly—Fighters of Defects Support Group

3032 Brereton St Pittsburgh, PA 15219 (412) 687-6437 5,7,10

Human immunodeficiency Virus (HIV)

See: AIDS

Hunter Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease

Hurler Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease

Hurler-Schole Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease



is:

Is This Going to be Sad?

A "Wolf-Hirschhorn family reunion" is a time to share tears and laughter

Wolf-Hirschhorn syndrome, a rare chromosomal disorder also known as 4p-, his parents, Tom and Becky, were told he would not live long and would never do the same things as other children. Although the syndrome was extremely rare, Becky believed there had to be other families out there. Ten years ago, when Craig was three years old, Becky sent a Search letter to Exceptional Parent. Over the next six months, she received eight responses. Those letters marked the start of the Wolf-Hirschhorn Parent Network.

Connections and hope

Because so little was known about the syndrome, Becky's first initiative was to set up an information exchange. Parents were asked to submit a biography of their child in exchange for receiving biographies of other children.

Sometimes these histories proved medically valuable as the experiences of others alerted "newer" parents that their children were at risk of developing seizure disorders, curvature of the spine and eye disease.

The biographies also provided feelings of connection and hope. Parents discovered that other children with the syndrome also love mirrors, balloons, music and motion. They learned that some do learn to walk, some can be toilet trained and even those with the most limited skills respond to love, enjoy rough-housing and unfailingly give the gift of a smile.

The group's first "get-together," held in Iowa in 1992, was attended by 25 families—mostly mothers and children. It was such a rewarding experience, they went home to encourage their husbands and other relatives to attend the next "Reunion."

Is this going to be sad?

But Christopher's father wasn't sure he really wanted to spend time with other families affected by his son's syndrome. "Is this going to be sad?" he asked upon arrival at the group's second Reunion.

Sara Wood, one of the event organizers, flung open the door to her family's hotel room. Inside were various members of four families—children with the syndrome, parents, siblings and a grandmother. The sounds of laughing, non-stop talking and children playing could be heard. Scattered



It wasn't sad: Enjoying an impromptu get-together at the second Wolf-Hirschhorn reunion are (from left) Stephanie Higgins, Wanda Hill, Christopher Hill, Craig Richardson (partially hidden), A.J. Grimmett, Christine Gold, Justin Furr, Kelly Gold and Brian Jungen.

about were suitcases, wheelchairs, photo albums and toys. "Does *this* look sad?" Sara asked.

The event, held in Asheville, North Carolina, drew families from as far away as California, Canada and Germany. Michelle, 23, was the oldest person with the syndrome at the reunion—she had been diagnosed only in the past year. Anthony, the youngest child, was 21 months old. Also attending were one foster family, two adoptive families and one family whose infant with the syndrome had died.

What a support to be with others...

The event gave families a chance to ask questions and share experiences. One mother probably summed up the experiences of many—"After I was here a little while, I just started crying... I can't tell you how happy I am that I came—just to see the other children, to see their ages, to meet their families. They feel like friends I have known all my life... What a support to be with others who also appreciate and love their children!"

And Christopher's father? He left the reunion with a smile on his face and said, "It wasn't sad."

-Christine N. Kleimola

Christine Kleimola is the adoptive mother of Rachael Melinda, 5. Christine and Rachael live in Ypsilanti, Michigan.



SPECIFIC DISABILITIES

Hydrocephalus

Guardians of Hydrocephalus Research Foundation

2618 Ave Z Brooklyn, NY 11235 (718) 743-4473 (718) 743-1171 (fax) (800) 458-8655 1.3.4.7.9

Hydrocephalus Association

870 Market St. Ste 955 San Francisco, CA 94102 (415) 776-4713 1,2,4,6,7

Hydrocephalus Support Group

PO Box 4236 Chesterfield, MO 63006-4236 (314) 532-8228

1.2.3.4.6.7

National Hydrocephalus Foundation

22427 S River Rd Joliet, IL 60436 (815) 467-6548 1,2,3,4,5,7,10

Hyperlexia

See also: Attention Deficit Disorder, Autism, Language Disorders

The American Hyperlexia Association

479 Spring Rd Elmhurst, IL 60126 (708) 530-8551 1.3.6.7

Hyperoxaluria

See: Oxalosis & Hyperoxaluria

Hyperthyroid Myopathy

See: Muscular Dystrophy

Hypogammaglobulinemia

See: Immune Disorders

Hypoglycemia

See also: Diabetes Mellitus

National Hypoglycemia **Association**

PO Box 120 Ridgewood, NJ 07451 (201) 670-1189 1,2,4,7,10

Hypopigmentation

See: Albinism & Hypopigmentation

Hypothyroid Myopathy

See: Muscular Dystrophy

Hypothyroidism, Congenital

See: Growth Disorders

Hypotonia, Benign Congenital

See: Spinal Muscular Atrophy

I-Cell Disease

See: Mucopolysaccharidosis, Tay-Sachs Disease

ichthyosis

FIRST: Foundation for Ichthyosis and Related Skin Types

PO Box 20921 Raleigh, NC 27619 (800) 545-3286 (919) 782-5728 (919) 781-0679 (fax) 1,2,4,5,6,7,8,10

Illiostom/

See: Ostomy

Iliness. Terminal

See also: Bereavement Support

Children's Hospice International

700 Princess St, Lower Level Alexandria, VA 22314 (800) 242-4453 (703) 684-0330 (703) 684-0226 (fax) 1,2,3,4,6,7,8

Immune Deficiency

See: Immune Disorders

Immune Disorders

See also: Autoimmune Disorders

Immune Deficiency Foundation

25 W Chesapeake Ave, Ste 206 · Towson, MD 21204 (800) 296-4433 (410) 321-6647 (410) 321-9165 (fax) 1.4.5.6.7.8.9.10

Imperforate Anus

See: Anorectal Malformations

Incontinence

Help for Incontinent People

PO Box 544 Union, SC 29379 (800) 252-3337 (803) 579-7900 (803) 579-7902 (fax) 1.7.8.10

Simon Foundation for Continence

PO Box 815 Wilmette, IL 60091 (800) 237-4666 (708) 864-3913 (708) 864-9758 (fax)

1.4.6.7.8.9

Incontinentia Piamenti

IP Support Network

c/o Colleen Kidder 34929 Elm Wayne, MI 48184 (313) 729-7912 1.4

Intestinal Psoudo-**Obstruction Syndrome**

American Pseudo-Obstruction and Hirschsprung's Disease Society

PO Box 772 Medford, MA 02155 (617) 395-4255 (617) 396-6868 (fax) 1.2.4.6.7.9.10

Intrauterine Growth Retardation

See: Growt' Disorders

Intraventricular Hemorrhage

IVH Parents

PO Box 56-1111 Miami, FL 33256-1111 (305) 232-0381 (305) 232-9890 (fax) ₹ 72167.633@compuserve.com 1,4,7,8,10

Jeune Syndrome

See: Growth Disorders

Johanson-Blizzard Syndrome

See: Growth Disorders, Schwachman Syndrome ·

Joubert Syndrome

Joubert Syndrome Parents-in-**Touch Network**

12348 Summer Meadow Rd Rock, MI 49880 (906) 359-4707 1.3.4.6

Kaliman Syndrome

See: Growth Disorders

Keratosis Foilicularis Spinulosa Decaivans

See: Ichthyosis

KID Syndrome

See: Hearing Impairments, Ichthyosis

Kidney Disorders

See also: Cystinosis, Oxalosis

American Kidney Fund

6110 Executive Blvd, Ste 1010 Rockville, MD 20852 (800) 638-8299 (301) 881-0898 (fax) 1,2,7,9, financial aid for treatment-related expenses

Kidney Foundation of Canada 5160 Blvd Decarie, Bureau 780

Montreal, PQ CAN H3X 2H9 (514) 369-4806 (514) 369-2472 (fax) 2,3,4,5,6,7,9

National Kidney Foundation

New York, NY 10016 (800) 622-9010 (212) 889-2210 (212) 689-9261 (fax) 1,2,3,5,6,7,8,9; publications for

pediatric kidney patients **Polycystic Kidney Research** Foundation

922 Walnut St, Ste 411 Kansas City, MO 64106 (800) 753-2873 (816) 421-1869 (816) 421-7208 (fax) 1.2.3.5.6.8.9.10

Kiviin Syndrome

See: Growth Disorders

Klinefelter Syndrome

49. XXXY Syndrome Association

10001 NE 74th St Vancouver, WA 98662-3801 (206) 892-7547 1,4,10

Klinefelter Syndrome and **Associates**

PO Box 119 Roseville, CA 95661-0119 1.4.6.10

Klinefelter's Syndrome **Association of America**

PO Box 93 Pine River, WI 54965 1,2,4,5,10

SEEKS: Support and Educational Exchange for Klinefelter Syndrome

1417 25th Ave Dr W Bradenton, FL 34205-6449 (813) 750-8044 1,4,10

Klippel-Trenaunay Syndrome

See also: Nevi, Giant Congenital; Sturge-Weber Syndrome, Vascular Malformations

Klippel-Trenaunay **Support Group**

c/o Judy Vessey 4610 Wooddale Ave Edina, MN 55424 (612) 925-2596 (612) 333-8685 (fax) vesse001@staff.tc.umn.edu 1.2.6

Krabbe Disease

See: Leukodystrophy, Tay-Sachs Disease

Kugelberg-Wolander Disease

See: Spinal Muscular Atrophy



Lactate Dokydrogenase Deficiency

See: Muscular Dystrophy

Lactic-Acidosis

See also: Neurometabolic Disorders

Lactic-Acidosis Support Group

PO Box 480282 Denver, CO 80248-0282 (303) 287-4953 1.4.5.7.10

Landau-Kleffner Syndrome

See also: Autism, Epilepsy, Language Disorders

CANDLE Support Group 4414 McCampbell Dr

Montgomery, AL 36106 (205) 271-3947 (voice/fax) 1,4,5,7,8,10

Landouzy-Delerine Dystrophy

See: Facio-Scapulo-Humeral Muscular Dystrophy

Langerhans Cell Histiocytosis

See: Histiocytosis

Language Disorders

See also: Aphasia. Acquired: Apraxia; Autism; Hyperlexia; Stutterina

TALK: Taking Action Against Language Disorders for Kids

22980 Donna Ln Bend, OR 97701 (503) 389 0004 1,2,4,5,7,10; sibling support

Laurence-Moon-Bardet-**Biedi Syndrome**

See also: Kidney Disorders, Retinitis Piamentosa

Laurence-Moon-Bardet-Biedl **Syndrome Network**

18 Strawberry Hill Windsor, CT 06095 (203) 688-7880

Learning Disabilities

See also: Attention Deficit Disorder, Dyslexia

Learning Disabilities **Association of America**

4156 Library Rd Pittsburgh, PA 15234 (412) 341-1515 (412) 344-0224 (fax) 1,2,3,5,6,7,8

Learning Disabilities **Association of Canada**

323 Chapel St, Ste 200 Ottawa, ON CAN K1N 7Z2 (613) 238-5721 (613) 235-5391 (fax) 1,2,3,6,8

National Center for Learning Disabilities

381 Park Ave S, Ste 1420 New York, NY 10016 (212) 545-7510 (212) 545-9665 (fax) 1,2,3,7,8,9; educational programs

Learning Disabilities & Cifted

See also: Attention Deficit Disorder, Dyslexia, Learning Disabilities

Parents of Gifted/LD Children

2420 Eccleston St Silver Spring, MD 20902 (301) 986-1422

Leigh's Disease

National Leigh's Disease **Foundation**

608 Waldron St, PO Box 2222 Corinth, MS 38834 (601) 287-8069 (601) 286-2551 (fax) 1,2,4,5,6,7,8,9,10

Laprosy

American Leprosy Missions

1 ALM Wy Greenville, SC 29601 (800) 543-3131 (803) 271-7040 (803) 271-7062 (fax) 1,2,3,4,6,7,9

Lesch-Nyhan Disease

International Lesch-Nyhan Disease Association

11042 Ferndale St Philadelphia, PA 19116 (215) 677-4206 1.4.10

Leukemia

Leukemia Society of America

600 Third Ave, 4th FI New York, NY 10016 (800) 954-4572 (212) 573-8484 (212) 856-9686 (fax) 1,2,3,5,6,7,8,9

Leukodystrophy

See also: Myelin Disorders, Tay-Sachs Disease

United Leukodystrophy **Foundation**

2304 Highland Dr Sycamore, IL 60178 (800) 728-5483 (815) 895-3211 (815) 895-2432 (fax) (815) 895-8633 (BBS, 9600 baud) dulf@ceet.niu.edu 1,2,3,4,6,11

Limb Disorders

See also: Amoutation

可光要素素

Cherub Association of Families and Friends of Children with **Limb Disorders**

936 Delaware Ave Buffalo, NY 14209 (716) 762-9997 1,4,5,7,10; summer camp

Superkids Newsletter 60 Clyde St Newton, MA 02160

1,2,4,10

Lissencephaly Lissencephaly Network

716 Autumn Ridge Ln Fort Wayne, IN 46804 (219) 432-4310 1.2.4.6.10: DNA testing, tov library

Liver Disorders

American Liver Foundation

1425 Pompton Ave Cedar Grove, NJ 07009 (800) 223-0179 (201) 256-2550 (201) 256-3214 (fax) 1,2,3,6,7,8,9,10

Canadian Liver Foundation

1320 Yonge St, Ste 301 Toronto, ON CAN M4T 1X2 (800) 563-5483 (Canada only) (416) 964-1953 (416) 964-0024 (fax) 1,2,3,5,6,7,8,9

Lowe Syndrome

See also: Growth Disorders, Visual **Impairments**

Lowe Syndrome Association

222 Lincoln St W Lafavette, IN 47906 (317) 743-3634 1,2,4,6,9,10

Lung Diseases

American Lung Association

1740 Broadway New York, NY 10019 (800) 586-4872 (212) 315-8700 (212) 265-5642 (fax) 5,6,8,9; programs for schools

Canadian Lung Association 1900 City Pk Dr, Ste 508 Gloucester, ON CAN K1J 1A3 (613) 747-6776 (613) 747-7430 (fax) 1,2,3,4,5,6,7,8,9

Key to Services

- 1. Periodical/newsletter
- 2. Other publications
- 3. Videos
- 4. Networking/matching
- 5. Local chapters
- National conferences
- 7. Referrals to local resources
- 8. National advocacy efforts
- 9. Fund research
- 10. Maintain registry of individuals with this condition
- 11. Electronic bulletin board (BBS)

Lupus Ervthematosus

American Lupus Society

260 Maple Ct, Ste 123 Ventura, CA 93003 (800) 331-1802 (info line) (805) 339-0443 1,2,4,5,6,7,9,10

Lupus Foundation of America

4 Research PI, Ste 180 Rockville, MD 20850-3226 (800) 558-0121 (800) 558-0231 (Spanish) (301) 670-9292 (301) 670-9486 (fax) 1,5,7,8,9

SLE Foundation

149 Madison Ave. Ste 608 New York, NY 10016 (212) 685-4118 (212) 545-1843 (fax) 1,2,5,6,7,9

Lyme Disease

Lyme Disease Foundation

1 Financial Plaza, Gold Bldg, 18th Fl Hartford, CT 06103-2610 (800) 886-5953 (info line) (203) 525-2000 (203) 525-8425 1,2,3,6,8,9,10

Lymphohisticcytosis, Familial Erythrophagocytic

See: Histiocytosis

Lymphohisticcytosis. Malignant

See: Cancer, Histiocytosis

Macular Diseases

See also: Retinitis Pigmentosa, Stargardt Disease, Usher Syndrome, Visual Impairments

Association for Macular Diseases

210 E 64th St New York, NY 10021 (212) 605-3719 1,7,8,9



Macular Degeneration Foundation

PO Box 686 Palm Beach, FL 33480 (407) 820-9215 1.7.10

Male Sex Chromosome Disorders

See: Klinefelter Syndrome

Malignant Hyperthermia

Malignant Hyperthermia Association of United States 32 S Main St, PO Box 1069 Sherburne, NY 13460

(800) 986-4287 (607) 674-7901 (800) 674-7910 (fax) 1,2,3,10

North American Malignant Hyperthermia Registry

Dept of Anesthesia, Penn State Univ PO Box 850 Hershey, PA 17033 (717) 531-6936 (717) 531-6221 (fax) 9,10; can provide detailed individual reports to physicians

Mannosidosis

See: Tay-Sachs Disease

Maple Syrup Urine Disease

See also: Acidemia, Organic; Neurometabolic Disorders

Maple Syrup Urine Disease Family Support Group

24806 State Rd 119 Goshen, IN 46526 (219) 862-2992 (219) 862-2012 (fax) 1,2,4,6,7

Marfan Syndrome

Canadian Marfan Association

Central Plaza Postal Outlet 128 Queen St S, PO Box 42257 Mississauga, ON CAN L5M 4Z0 (905) 826-3223 (905) 826-2125 (fax) 1,3,4,5,6,10

National Marfan Foundation

382 Main St Port Washington, NY 11050 (800) 862-7326 (516) 883-8712 (voice/fax) 1,2,3,4,5,6,8,9,10

Maroteaux-Lamy Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease

McArdie Disease

See: Glycogen Storage Disease

McCune-Albright Syndrome

See also: Growth Disorders

McCune-Albright Syndrome Division of the MAGIC Foundation

3167 Greensburg Rd N Canton, OH 44720 (216) 896-4455 1,4,6,10

Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)

See also: Neurometabolic Disorders

Support Group for MCAD

805 Montrose Dr Greensboro, NC 27410 (910) 547-8682 1,4,10

Medullobiastoma, Hereditary

See: Brain Tumors, Turcot Syndrome

MELAS Syndrome

See: Growth Disorders

Meinick Needles Syndrome

See: Growth Disorders

Menke's Disease

Corporation for Menke's Disease

5720 Buckfield Ct Fort Wayne, IN 46804 (219) 436-0137 1,2,3,4,6,7,10; physician network

Montal Kiness

See also: Mental Retardation/ Mental Illness

Federation of Families for Children's Mental Health

1021 Prince St Alexandria, VA 22314-2971 (703) 684-7710 (703) 684-5968 (fax) ■ paulcazzolla@mmp.org 1.2.4.5.7.8.10

National Mental Health Association

1021 Prince St Alexandria, VA 22314-2971 (800) 969-6642 (info line) (703) 684-7722 (703) 684-5968 (fax) 1,2,4,5,6,7,8; public-education

Mental Retardation

The Arc

Foo E Border St, Ste 300 PO Box 1047 Arlington, TX 76010 (800) 433-5255 (817) 261-6003 (817) 277-0553 (TTY) (817) 277-3491 (fax) thearc@metro.com 1,2,3,5,6,7,8,9

Canadian Association for Community Living

4700 Keele St
Kinsman Bldg, York University
North York, ON CAN M3J 1P3
(416) 661-9611 (voice)
(416) 661-2023 (TTY)
(416) 661-5701 (fax)
1,2,5,6,7,8,9; lending library for videotapes and other materials

Voice of the Retarded

5005 Newport Dr, Ste 108 Rolling Meadows, IL 60008 (708) 253-6020 1,3,5,7,8; free legal consulting

Mental Retardation/ Mental liness

See also: Mental Illness

National Association of the Dually Diagnosed (NADD)

110 Prince St Kingston, NY 12401 (800) 331-5362 (914) 331-4336 (914) 331-4569 (fax) 1,3,4,5,6,7

Metabolic Disorders

See: Neurometabolic Disorders

Microphthalmia

See: Visual Impairments

Microsomia, Hemifaciai

See: Craniofacial Disorders, Goldenhar Syndrome

Microtia

See also: Craniofacial Disorders

Microtia-Atresia Support Group

c/o Jack Gross 330 7th Ave, #1203 New York, NY 10001 (212) 947-0770 4,7,10

Miller Syndrome

See: Nager & Miller Syndromes

Miller-Dicker Syndrome

See: Lissencephaly

Mitachondrial Disorders

EASE: Education and Support Exchange

PO Box 1151 Monroeville, PA 15146-1151 1,4,10

Mitochondrial Disorders

Mitochondrial Disorders Foundation of America

5100-1B Clayton Rd, Ste 187 Concord, CA 94521 (510) 798-8798 (510) 682-1477 (fax) 1,4,7,8,9,10

Mitochondrial Myopathy

See: Mitochondrial Disorders, Muscular Dystrophy

Moebius Syndrome

See also: Craniofacial Disorders

Moebius Syndrome Support Group

39521 Rowen Ct Palmdale, CA 93551 (805) 267-2570 (310) 470-2000 (914) 834-6008 1,4,6,9,10

Morquio Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease

Motor-Sensory Neuropathy, Kereditary

See: Charcot-Marie-Tooth Disease

Moyamoya Disease

See also: Vascular Malformations

Families with Moyamoya Network

c/o Dawn Gruettner 4900 McGowan St SE Cedar Rapids, IA 52403 (800) 261-6692 1.4.10

Mucolipidoses

See: Mucolipidosis Type IV, Mucopolysaccharidosis, Tay-Sachs Disease

Mucolipidosis Type IV

See also: Mucopolysaccharidosis, Tay-Sachs Disease

ML4 Foundation

6 Concord Dr Monsey, NY 10952 (914) 425-0639 (914) 425-4205 (fax) 4,7,9,10

Mucopolysaccharidosis

See also: Tay-Sachs Disease

National Mucopolysaccharidosis Society

17 Kraemer St Hicksville, NY 11801 (516) 931-6338 1,2,3,4,5,6,7,8,9,10



MPS: The Ties That Bind

The National MPS Society offers an extended family of love and support

amily is your greatest strength. Marie Capobianco first discovered this when her children, Michael and Danielle, were diagnosed with Sanfillippo-B syndrome, one of seven mucopoly-saccharidosis (MPS) disorders. She discovered it again as president of the National MPS Society.

MPS and ML (mucolipidosis) disorders are progressive, enzyme-deficiency conditions, in which the cells of the body cannot produce the enzyme which breaks down sugars or fats in the cell. These products build up, causing pressure on and damaging other cells, including nerve cells. This can lead to mental retardation, limited mobility, extreme hyperactivity and drastically shortened life spans. Few children with MPS and ML survive

their teen years. The National MPS Society was created to support families living with these difficult conditions.

When 10 pairs of anxious parents first met in a conference room at Johns Hopkins Hospital in February of 1974, they were determined to see something done for their children. One year later, led by Capobianco, a solid network of parents had been established.

Through phone calls, letters and local and national meetings, parents are able to share every-

thing from the latest research information, to anecdotes of life with an "MPS kid," to the pain of losing that child only a short time later. This is the true work of the MPS Society—the continuing support of parents worn thin by children difficult to care for and taken away too soon. At the group's 20th anniversary celebration in Kissimmee, Florida in December 1994, Joni Carso, the mother of a child with MPS I, explained how it felt to spend time with similar families—"You can sit down to dinner and when [your child] starts screeching, no one will stare at you and say, 'Oh, no."

It is this sense of belonging to an understanding family that keeps parents involved in the organization even after their children die. Many feel even stronger ties to the group, bound by memories and by friends who continue to lend support. In a letter published in a recent edition of the society's newsletter, Susan Teer, who recently lost her daughter Sarah, captured part of this connection between MPS parents—"We know that these are not easy times for any of us... If we can get another

family through a moment, we will be here to listen and to share their happiness or sadness... Our hearts reach out to all of you."

Like Susan, Marie Capobianco



[Above] Marie
Capobianco (right), MPS
president spends some
time with the Kahn family at the group's 20th
annual conference in
Kissimmee, Florida.
[Left] A wall of faces—
pictures of members' chil
dren—was a focus point
at the conference.

continues to feel a strong bond to the society, even though both Michael and Danielle passed away recently. And like so many others, she plans to stay involved in the continuing work of the group. As Marie and her family learned to live with Sanfillippo-B syndrome, her involvement with the MPS Society gave her comfort while allowing her to comfort others. "I wanted to show [other parents] that you could feel guilt and pain and love and hate towards your child and not be ashamed," she said. Over the years, Marie and the other parents involved with the MPS society have helped each other realize that the myriad emotions evoked by the experience of parenting a child with a terminal illness are legitimate and human. In doing so they have helped each other cope.

-Jennifer M. Koerber

Multiple Scierosis

National Multiple Scierosis Society

733 3rd Ave, 6th Fi New York, NY 10017 (800) 344-4867 (212) 986-3240 (212) 986-7981 (fax) 1,2,3,6,7,8,9

Multiple Sulfatase Deficiency

See: Hearing Impairments. Ichthyosis, Leukodystrophy, Tay-Sachs Disease

Muscular Atrophy, Peroneal

See: Charcot-Marie-Tooth Disease

Muscular Dystrophy

See also: Facio-Scapulo-Humeral Muscular Dystrophy, Ventilator Use

Muscular Dystrophy **Association** 3300 F. Sunrise Dr

Tuscon, AZ 85718-3208 (800) 572-1717 (602) 529-2000 (602) 529-5300 (fax) (After March 1, 1995, 602 area code changes to 520) № 74431 2513@compuserve.com 1,2.4,5,7.9; outpatient clinics,

Muscular Dystrophy Association of Canada

150 Eglinton Ave E, Ste 400 Toronto, ON CAN M4P 1E8 (800) 567-2873 (Canada only) (416) 488-0030 (416) 488-7523 1,2,4,5,6,7,8,9; provides equipment to families

financial assistance, genetic

counseling, summer camps

Myasthenia Gravis

See: Muscular Dystrophy

Myelin Disorders

The Myelin Project 1747 Pennsylvania Ave NW Ste 950 Washington, DC 20006 (202) 452-8994 (202) 785-9578 (fax) 1,9,10

The Myelin Project of Canada

c/o Julie and Wayne Simmons 4330 Spinningdale Crt Mississauga, ON CAN L5M 3J8 (905) 567-8843 (905) 567-9189 (fax) 1,3,4,6,7,8,9,10

Myelin, insufficient

Myelin Messenger Newsletter

c/o Ruth Anderson HC-29, Box 686 Stable Ln Prescott, AZ 86301-7435 (602) 776-7556 (After March 1, 1995, GJ2 area code changes to 520)

Myelodyspiasia

See: Anemia, Aplastic

Myoclonus

See also: Opsocionus-Myocionus Syndrome

Myoclonus Families United

1564 E 34th St Brooklyn, NY 11234 (718) 252-2133

Myedenylate Deaminase Deficiency

See: Muscular Dystrophy

Myositis

See also: Autoimmune Disorders

National Support Group for Myositis

PO Box 890 Cooperstown, NY 13326 (800) 230-0441 (607) 547-5216 1,4,10

Myositis Ossificans Progressiva

See: Fibrodysplasis Ossificans Progressiva

Myotonia Congenita

See: Muscular Dystrophy

Myotubular Myopathy

See also: Muscular Dystrophy

X-Linked Myotubular **Myopathy Resource Group**

2413 Quaker Dr Texas City, TX 77590 (409) 945-8569 1.4.10

Myxedema

See: Thyroid Disorders

N-Acetyl Glutamate Synthetase (NAGS) **Deficiency**

See: Urea Cycle Disorders

Nager & Miller Syndromes

See also: Craniofacial Disorders. Limb Disorders

Foundation for Nager and Miller Syndromes (FNMS)

333 Country Ln Glenview, IL 60025-5104 (800) 507-3667 (708) 724-6449 (voice/fax) 1,4,7,8,9,10; lending library, camp scholarships

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Nasai Encepholocele

See: Craniofacial Disorders

Nemaline Myopathy

See: Muscular Dystrophy

Neonatal Iliness/ **Prematurity**

Parent Care 9041 Colgate St Indianapolis, IN 46268-1210 (317) 872-9913 (317) 872-0795 (fax) 1.2.4.6.7

Netherton Syndrome

See: Ichthyosis

Neurofibromatosis

See also: Acoustic Neuroma

National Neurofibromatosis Foundation

95 Pine St, 16th FI New York, NY 10005 (800) 323-7938 (V/TTY) (212) 344-6633 (212) 747-0004 (fax) MNFF@aol.com 1,2,4,5,7,9,10; medical conferences and symposia

Meurofibramatosis Institute

5415 Briggs Ave La Crescenta, CA 91214 (818) 957-3508 (818) 957-4926 (fax) 73044.2707@compuserve.com 4,7,8,9

Neurofibromatosis, Inc.

8855 Annapolis, Ste 110 Lanham, MD 20706-2924 (800) 942-6825 (301) 577-8984 (410) 461-5213 (TTY) (301) 577-0016 (fax) 1,2,3,5,7,8,9,10

Neurometabolic Disorders

See also: Acidemia, Organic: Galactosemia; Lactic-Acidosis; Maple Syrup Urine Disease; Niemann-Pick Disease; Phenylketonuria (PKU)

Association for **Neurometabolic Disorders**

5223 Brookfield Ln Sylvania, OH 43560-1809 (419) 885-1497 1,4,6,10

Canadian Society for **Metabolic Disease**

5301 Ranger Ave N Vancouver, BC CAN V7R 3M7 (604) 986-2508 (604) 293-7126 (fax) 1,2,3,4,5,6,7,8,9,10

Neuropathy, Hereditary Motor-Sensory

See: Charcot-Marie-Tooth Disease

Neuropathy, Peripheral

See: Charcot-Marie-Tooth Disease

Neutropenia

See: Evans Syndrome

Neutropenia with Pancreatic Insufficiency

See: Schwachman Syndrome

Nevi, Giant Congenital

See also: Hemangioma. Ichthyosis, Klippel-Trenaunay Syndrome, Sturge-Weber Syndrome, Vascular Malformations

Nevus Network

1400 S Joyce St, #1225 Arlington, VA 22202 (703) 920-2349 (405) 377-3403 syfv45b@prodigy.com 1,2,4,10

Neville Disease

See: Niemann-Pick Disease

Niemann-Pick Disease

See also: Ataxia, Neurometabolic Disorders, Tay-Sachs Disease

National Niemann-Pick **Disease Foundation**

22201 Riverpoint Trail Carrollton, VA 23314 (804) 357-6774 1.4.6.7.9.10

Nochan Syndrome

See also: Cardio-Facio-Cutaneous Syndrome, Growth Disorders

Noonan Syndrome Society

c/o Susan Espinoza 128 Pine Ave San Jose, CA 95125 (408) 723-5188 1,2,3,4,6,7,10

Occulo-Auricular-Vertebral (OAV) Syndrome

See: Goldenhar Syndrome

Obsessive-Compulsive Disorder

OC Foundation

PO Box 70 Milford, CT 06460 (203) 878-5669 1,2,3,4,5,6,7,9

Oilgosaccharisdoses

See: Tay-Sachs Disease

Ollier's Disease

Ollier's Disease Self-Help Group

PO Box 52616 Shaw AFB, SC 29152-1521 1,4,7



Opitz Syndrome

See also: Agenesis of the Corpus Callosum

International Optiz-Frias Syndrome Association

116 June Ave Nanaimo, BC CAN V9S 4R7 (604) 754-7088 (604) 758-5504 (fax) 4.7.8.10

Opitz Family Network

PO Box 516 Grand Lake, CO 80447 (303) 627-8935 1,4,6,10

Opitz-Frias Syndrome

See: Opitz Syndrome

Oppenheim Disease

See: Spinal Muscular Atrophy

Opsocionus-Myocionus Syndrome

See also: Myocionus

Opsocionus-Myocionus Parent-Taik Support Network

c/o Connie Quinn 725 North St Jim Thorpe, PA 18229 (717) 325-3302 1,4

Optic Nerve Hypopiasia

See: Septo-Optic Dysplasia

Organic Acidemia

See: Acidemia, Organic

Ornithine Transcarbamylase (OTC) Deficiency

See: Urea Cycle Disorders

Osteogenesis Imperfecta

See also: Growth Disorders

Canadian Osteogenesis Imperfecta Society

128 Thornhill Crescent Chatham, ON CAN N7L 4M3 1,4,6,7,9

Osteogenesis Imperfecta Foundation

5005 W Laurel St, Ste 210 Tampa, FL 33607 (813) 282-1161 (813) 287-8214 (fax) 1,2,3,4,5,6,7,8,9,10

Ostomy

United Ostomy Association

36 Executive Pk, Ste 120 Irvine, CA 92714-6744 (800) 826-0826 (714) 660-8624 (714) 660-9262 (fax) 1,2,3,5,6,7

Oxalosis & Hypercxaluria

See also: Kidney Disorders

Oxalosis & Hyperoxaluria Foundation

PO Box 1632 Kent, WA 98035 (206) 631-0386 1,2,4,6,7,8,9,10

Pachygyria

See: Lissencephaly

Pallister-Killian Syndrome

Pallister-Killian Family Support Group

3700 Wyndale Ct Ft Worth, TX 76109 (817) 927-8854 (817) 927-2073 (fax) 4,10

Pancreatic insufficiency with Neutropenia

See: Schwachman Syndrome

Panhypopituitarism

See: Diabetes Insipidus, Growth Disorders

Papiliomas

See: Respiratory Papillomatosis, Recurrent

Paralysis, Periodic

See: Muscular Dystrophy

Paramyotonia Congenita

See: Muscular Dystrophy

Peilzaeus-Merzbacher Disease

See: Leukodystrophy

Pemphigus, Familiai

See: Ichthyosis

Pervasive Developmental Disorder (PDD)

See: Autism

Peutz-Jeghers Syndrome

See also: Polyposis

International Peutz-Jeghers Support Group

c/o Jill D. Brensinger Johns Hopkins Hospital 550 N Broadway, Ste 108 Baltimore, MD 21205 (410) 614-4038 (410) 614-9544 (fax) 1,4,7,10

Phenyiketonuria (PKU)

See also: Neurometabolic Disorders

Children's PKU Network

10515 Vista Sorrento Pkwy San Diego, CA 92121 (619) 587-9421 (619) 450-5034 (fax) 1,4,7,10; scholarships

National PKU News

c/o Virginia Schuett 6869 Woodlawn Ave NE, Ste 116 Seattle. WA 98115-5469 (206) 525-8140 (206) 525-5023 (fax)

Phosphofructokinase Deficiency

See: Muscular Dystrophy

Phosphoglycerate Kinase Deficiency

See: Muscular Dystrophy

Phosphoglycerate Mutase Deficiency

See: Muscular Dystrophy

Phosphorylase Deficiency

See: Muscular Dystrophy

Pierre Robin Syndrome

See: Craniofacial Disorders, Growth Disorders

Pigment Disorders

See: Albinism & Hypopigmentation, Vitiligo

Pituitary/Hypothalamus Disorders

See: Diabetes Insipidus

Pityriasis Rubra Pilaris

See: Ichthyosis

Polymyositis

See: Muscular Dystrophy, Myositis

Felvostotic Fibrous Dysp 'n

See: McCune-Aungnt Syndrome

Polyposis

See also: Peutz-Jéghers Syndrome

Familiai Gastrointestinal Cancer Registry

Mount Sinai Hospital 600 University Ave, Ste 1157 Toronto, ON CAN M5G1X5 (416) 586-8334 (416) 586-8644 (fax) 1,2,3,4,7,8,10; genetic counseling, predictive testing

Intestinal Multiple Polyposis and Colorectal Cancer

c/o Ann Fagan Reese's Crest, PO Box 11 Conyngham, PA 18219 (717) 788-1818 (717) 788-3712 (717) 788-4046 (fax) 4.7.10

Pompe Disease

See: Glycogen Storage Disease, Tay-Sachs Disease

Key to Services

- 1. Periodical/newsletter
- 2. Other publications
- 3. Videos
- 4. Networking/matching
- 5. Local chapters
- 6. National conferences
- 7. Referrals to local resources
- 8. National advocacy efforts
- 9. Fund research
- 10. Maintain registry of individuals with this condition
- 11. Electronic bulletin board (BBS)

Perphyrla

American Porphyria Foundation

P0 Box 22712 Houston, TX 77227 (713) 266-9617 1,2,4,7

Prader-Willi Syndrome

Prader-Willi Foundation

223 Main St Port Washington, NY 11050 (800) 253-7993 (516) 944-3173 (fax) 1,7,8,9

Prader-Willi Syndrome Association

2510 S Brentwood Blvd, Ste 220 St. Louis, MO 63144 (800) 926-4797 1,2,3,4,5,6,7,8,9,10

Prader-Willi Syndrome International Information Forum

40 Holly Ln
Roslyn Heights, NY 11577
(800) 358-0682
(516) 484-7154 (fax)

25 visink@delphi.com
1,2,4,6,7,8,10

Prematurity

See: Neonatal Illness/Prematurity

Progeria

4.8.10

International Progeria Registry c/o W. Ted Brown, MD. Ph.D. NY State Inst for Basic Research in Developmental Disabilities 1050 Forest Hill Rd Staten Island, NY 10314 (718) 494-5333 (718) 494-1026 (fax)

Proteus Syndrome

See: Neurofibromatosis



37

Prune Belly Syndrome

Prune Belly Syndrome Network

1005 E Carver Rd Tempe, AZ 85284 (602) 838-9006 (fax) (After March 1. 1995, 602 area code changes to 520) 1.7.8

Pseudo-Hurier Polydystrophy

See: Mucopolysaccharidosis, Tay-Sachs Disease

Pseudoxanthoma Elasticum (PXE)

National Association for Pseudoxanthoma Elasticum

1884 Cherry St Denver, CO 80220-1146 (303) 321-6347 1,7,10

Psoriasis

Canadian Psoriasis Foundation 1306 Wellington St, Ste 500A Ottawa, ON CAN K1Y 3B2 (800) 265-0926 (Canada only) (613) 728-4000 (613) 728-8913 (fax) 1.2.4.5.6.7.8.9

National Psoriasis Foundation 6600 SW 92nd, Ste 300

Portland, OR 97223 (503) 244-7404 (503) 245-0626 (fax) 1,2,3,4,7,8,9,10; correspondence network, used equipment, SSI information, help with insurance claims

Ptosis

See: Blepharophimosis

Purine Metabolic Disorders

Purine Research Society 5424 Beech Ave Bethesda, MD 20814

(301) 530-0354 4,7,9,10

Rasmussen Syndrome

See also: Epilepsy, Seizure Disorders

Rasmussen Syndrome Support Group

c/o Al and Lynn Miller 8235 Lethbridge Rd Millersville, MD 21108 (410) 987-5221 4.10

Reflex Sympathetic Dystrophy Syndrome

Reflex Sympathetic Dystrophy Association

116 Haddon Ave, Ste D Haddonfield, NJ 08033 (609) 795-8845 (voice/fax) 1,4,5,6,7,9,10

Refsum Disease

See: Ichthyosis, Leukodystrophy, Tay-Sachs Disease

Renai Disorders

See: Kidney Disorders

Respiratory Papillomatosis, Recurrent

Recurrent Respiratory Papillomatosis Foundation

50 Wesleyan Dr Hamilton, NJ 08690 (609) 890-0502

™ mstern@pucc.princeton.edu 1,2,3,4,5,6,7,8,10

Retinitis Pigmentosa

See also: Macular Diseases, Stargardt Disease, Usher Syndrome, Visual Impairments

Retinitis Pigmentosa International Society for Degenerative Eye Diseases

PO Box 900 Woodland Hills, CA 91365 (800) 344-4877 (818) 992-0500 (818) 992-3265 (fax) 1.2,3,5,7,8,9,10

RP Eye Research Foundation

c/o Sharon Cole 366 Adelaide St W, Ste 704 Toronto. ON CAN M5V 1R9 (800) 461-3331 (Canada only) (416) 598-4951 (416) 598-9763 (fax) 1,2,5,7,9,10

The Foundation Fighting Blindness

1401 Mt Royal Ave, 4th Fl Baltimore, MD 21217 21217-4245 (800) 683-5555 (800) 683-5551 (TTY) (410) 225-9400 (410) 225-9409 (TTY) (410) 225-3936 (fax) 1.4.5.6.7.9.10

Retinoblastoma

See also: Visual Impairments

National Retinoblastoma Parent Group

110 Allen Rd Bow, NH 03304 (603) 224-4085 1,4,6,10

Retinopathy of Prematurity (ROP)

See also: Visual Impairments

Prevent Blindness in Premature Babies

c/o Margaret Wilson PO Box 44792 Madison, WI 53744-4792 1,4,7,8,10

Rett Syndrome

Canadian Rett Syndrome Association

555 Fairway Rd Kitchener, ON CAN N2C 1X4 (416) 494-1954 (519) 893-1169 1,5,6,7,9,10

International Rett Syndrome Association

9121 Piscataway Rd, Ste 2B Clinton, MD 20735 (800) 818-7388 (301) 856-3334 (301) 856-3336 (fax)

Reys Syndrome

See: Medium-Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)

Ring Chromosome 18

See: Chromosome 18 & 13 Disorders

RSH Syndrome

See: Smith-Lemli-Opitz Syndrome

Rubinstein-Taybi Syndrome Rubinstein-Taybi Parent Group

c/o Lorrie Baxter PO Box 146 Smith Center, KS 66967 (913) 697-2984 1.2.4,6,10

Russeli-Silver Syndrome

See also: Growth Disorders, Short Stature

Association for Children with Russell-Silver Syndrome

22 Hoyt St Madison, NJ 07940 (201) 377-4531 (201) 822-2715 (fax) Madistribution (fax) Madistribution (fax)

Sanfillippo Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease

Scheie Syndroma

See: Mucopolysaccharidosis, Tay-Sachs Disease

Schwechman Syndrome

See also: Growth Disorders

Schwachman Syndrome Support Services c/o Joan Mowery

44 Meadowlark Rd Vernon, CT 06066 (203) 870-5454 1,4,7,10

Scieroderma

See also: Arthritis, Autoimmune Disorders

National Scleroderma Federation

Peabody Office Bldg One Newbury St Peabody, MA 01960 (800) 422-1113 (508) 535-6600 (508) 535-6696 (fax) 1.2,5,7,8,9

Scleroderma Research Foundation

PO Box 200 Columbus, NJ 08022 (800) 637-4005 (609) 723-7400 (609) 723-6700 (fax) 1,4,7,9,10

United Scleroderma Foundation

PO Box 399 Watsonville, CA 95077-0399 (800) 722-4673 (408) 728-2202 (408) 728-3328 (fax) 1.2.5.6.9

Scoliosis

National Scoliosis Foundation

72 Mount Auburn St Watertown, MA 02172 (617) 926-0397 (617) 926-0398 (fax) 1,4,5,6,7,10

Seckei Syndrome

See: Growth Disorders

See also: Epilepsy

THRESHOLD: Intractable Seizure Disorder Support Group & Newsletter

26 Stavola Rd Middletown, NJ 07748-3728 (908) 957-0714

Septo-Optic Dysplasia

See also: Visual Impairments FOCUS: For Our Children's

Unique Sight 1583 Black Eagle Dr, Apt D San Diego, CA 92126 (619) 271-8488 (voice/fax)

pilarh8826@aol.com

Severe Combined Immunodeficiency (SCID)

See: Immune Disorders
Sax Chromosome Disorders,

Male

See: Klinefelter Syndrome





Short Stature

See also: Dwarfism, Growth Disorders

Little People of America

PO Box 9897 Washington, DC 20016 (800) 243-9273 (info line) (301) 589-0730 1,2,4,5,6

Shprintzen Syndrome

See: DiGeorge Syndrome, Velo-Cardio-Facial Syndrome

Sialidosis

See: Mucopolysaccharidosis, Tay-Sachs Disease

Sickie Cell Disease

Sickle Cell Disease Association of America

200 Corporate Pointe, Ste 495 Culver City, CA 90203-7633 (800) 421-8453 (310) 216-6363 (310 215-3722 (fax) 1,2,3,5,6,7,8

Triad Sickle Cell Anemia Foundation

1102 E Market St Greensboro, NC 27420-0964 (800) 733-8297 (910) 274-1507 (910) 275-7984 (fax) 1,4,7; genetic counseling, camp

Skeletal Dysplasia

See: Dwarfism, Growth Disorders, Short Stature

Sly Syndrome

See: Mucopolysaccharidosis, Tay-Sachs Disease

Smith-Lemil-Opitz Syndrome

Smith-Lemil-Opitz Advocacy & Exchange

222 Valley Green Dr Aston, PA 19014 (215) 494-5287 1,4,10

Smith-Magenis Syndrome

PRISMS: Parents & Researchers Interested in Smith-Magenis Syndrome

11875 Fawn Ridge Ln Reston, VA 22094 (703) 709-0568 (3) acmsmith@nchgr.nih.gov 1.2,4,7,10

Sotos Syndrome

See also: Epilepsy, Growth Disorders, Learning Disabilities, Obsessive-Compulsive Disorder

Sotos Syndrome USA Support Association

2333 W El Moro Mesa, AZ 85202 (602) 890-1722 (602) 890-2983 (fax) (After March 1, 1995, 602 area code changes to 520) 1,2,3,4,5,6,7,8,9,10

Spastic Paraplegia, Familiai

See: Ataxia

Speech Disorders

See: Aphasia, Apraxia, Autism, Language Disorders, Stuttering

Spina Bifida

See also: Arnold-Chiari Malformation, Hydrocephalus, Incontinence

Spina Bifida Association of America

4590 MacArthur Blvd NW, #250 Washington, DC 20007-4226 (800) 621-3141 (202) 944-3285 (202) 944-3295 (fax) 1,2,3,5,6,7

Spina Bifida Association of Canada

220-388 Donald St Winnipeg, MB CAN R3B 2J4 (800) 565-9488 (Canada only) (204) 957-1784 (204) 957-1794 (fax) 1,5,6,8,9

Spinal Cord Injuries

American National Spinal Cord Injury Hotline

2201 Argonne Dr Baltimore, MD 21218 (800) 526-3456 (410) 366-2325 (fax) 5,7,10

American Paralysis Association

500 Morris Ave Springfield, NJ 07081 (800) 225-0292 (201) 379-2690 (201) 912-9433 (fax) 1,7,9,10

National Spinal Cord injury Association

545 Concord Ave, Ste 29 Cambridge, MA 02133 (800) 962-9629 (hotline only) (617) 441-8500 (617) 441-3449 (fax.) 1,2,4,5,6,7,8,9,10

Spinal Muscular Atrophy

See also: Muscular Dystrophy, Ventilator Use

Families of SMA

PO Box 1465 Highland Park, IL 60035-7465 (800) 886-1762 (708) 432-5551 (voice/fax) 1,3,4,5,6,7,8,9,10

Spondyloepiphyseal Dysplasia Congentia

See: Growth Disorders

Stargardt Disease

See also: Macular Diseases, Retinitis Pigmentosa, Visual Inipairments

Stargardt International and Juvenile Macular Dystrophies

c/o Macular Degeneration Inti 2968 W Ina Rd, #106 Tucson, AZ 85741 (602) 797-2525 (voice/fax) (After March 1, 1995, 602 area code changes to 520) 1.4.6.7.9.10

Sturge-Weber Syndrome

See also: Klippel-Trenaunay Syndrome; Nevi, Giant Congenital: Vascular Malformations

Sturge-Weber Foundation

PO Box 418 Mt Freedom, NJ 07970 (800) 627-5482 (201) 895-4445 (201) 895-4846 (fax) 1,2,3,4,6,7,8,10

Sturge-Weber Foundation— Canada

1960 Prairie Ave Port Coquitlam, BC CAN V3B 1V4 (604) 942-9209 (604) 942-6429 (fax) 4.5.7.10

Stuttering

National Center for Stuttering

200 E 33rd St New York, NY 10016 (800) 221-2483 (212) 532-4445 (fax) 7.10

National Stuttering Project

2151 Irving St, Ste 208 San Francisco, CA 94122-1609 (800) 364-1677 (415) 566-5324 (415) 664-3721 (fax) 1,5,6,7,8,10

Speak Easy

c/o Mike Hughes 95 Evergreen Ave St John, NB CAN E2N 1H4 (506) 696-6799 (506) 657-1224 (fax) 1,5,7,8

39

Key to Services

- 1. Periodical/newsletter
- 2. Other publications
- 3. Videos
- 4. Networking/matching
- 5. Local chapters
- 6. National conferences
- 7. Referrals to local resources
- 8. National advocacy efforts
- 9. Fund research
- Maintain registry of individuals with this condition
- 11. Electronic bulletin board (BBS)

Stuttering Foundation

of America
PO Box 11749
Memphis, TN 38111-0749
(800) 992-9392
(901) 452-7343
(901) 452-3931 "fax)

☑ stuttersfa@aoi.com
1,2,3,6,7,8

Stuttering Resource Foundation

123 Oxford Rd New Rochelle, NY 10804 (800) 232-4773 (914) 632-3925 (914) 235-0615 (fax) 24 esr1@iona.bitnet 1.2.7

Sudden Infant Death Syndrome (SIDS)

See also: Bereavement Support

National Sudden Infant Death Syndrome Resource Center 8201 Greensboro Dr. Ste 600

McLean, VA 22102 (703) 821-8955 (703) 821-2098 (fax) 1,2,7

Sudden Infant Death Syndrome Alliance

1314 Bedford Ave, Stc 108 Baltimore, MD 21208 (800) 221-7437 (410) 653-8226 1,6,7,8,9

Sudeck Atrophy

See: Reflex Sympathetic Dystrophy Syndrome

Sulfatidosis

See: Hearing Impairments, Ichthyosis. Leukodystrophy, Tay-Sachs Disease

Syringobulbla

See: Syringomyelia

Syringomyella

See also: Arnold-Chiari Malformation

American Syringomyelia Alliance Project

PO Box 1586 Longview, TX 75606-1586 (800) 272-7282 (903) 236-7079 (903) 757-7456 (fax) 1,3,4,6,10

Canadian Syringomyelia Network

65 Huntingdale Blvd, #1607 Scarborough, ON CAN M1W 2P1 (416) 498-8097 (416) 750-8197 (fax) 1,4,6,7,8

Tangier Disease

See: Tay Sachs Disease

Tay Syndrome

See: Ichthyosis

Tay-Sachs Disease

National Tay-Sachs and Allied Diseases Association

2001 Beacon St, Ste 204 Brookline, MA 02146 (617) 277-4463 (617) 277-0134 (fax) 1,2,3,4,5,6,7,8,9,10; lending library

Tetrasomy 15

See: Chromosome 15 Disorders

Tetrasomy 18

See: Chromosome 18 & 13 Disorders

Thalassemia

See: Cooley's Anemia

Thrombocytopenia

See: Evans Syndrome

Thrombocytopenia Absent Radius (TAR) Syndrome

Thrombocytopenia Absent Radius Syndrome Association

212 Sherwood Dr, RD 1 Linwood, NJ 08221-9745 (609) 927-0418 1.4,7,10

Thyroid Disorders

See also: Graves Disease

Thyrold Foundation of Canada 1040 Gardeners Rd, Ste C Kingston, ON CAN K7P 1R7 (613) 634-3426

(613) 634-3483 (tax) 1,5,6,7,9,10

Tourette Syndrome

See also: Attention Deficit Disorder, Obsessive-Compulsive Disorder

Tourette Syndrome Association

42-40 Bell Blvd Bayside, NY 11361-2861 (800) 237-0717 (718) 224-2999 (718) 279-9596 (fax) 1,2,3,5,6,7,9,10

Tourette Syndrome Foundation of Canada

238 Davenport Rd, Box 343 Toronto, ON CAN M5R 1J6 (800) 361-3120 (Canada only) (416) 351-7757 (416) 351-9267 (fax) 1,2,3,4,5,6,7,8,9,10; camp

Tracheoesophageal Fistula (TEF)

See: VATER Association

Tracheostomy

Tracheostomy Support Group
144 Elmwood

Barberton, OH 44203 (216) 745-4392 4.7.8.10

Treacher Collins Syndrome

See also: Craniofacial Disorders

Treacher Collins Foundation PO Box 683

Norwich, VT 05055 (800) 823-2055 (802) 649-3050 1,2,3,4,6

Tremor

International Tremor Foundation

833 W Washington Blvd Chicago, IL 60607 (312) 733-1893 1.2.4.7.8.9.10

Trichotiliomania

See: Obsessive-Compulsive Disorder

Trisomy 13, 18 & Related Disorders

See: Chromosome 18 & 13 Disorders

Tuberous Scierusis

See also: Autism, Epilepsy, Learning Disabilities

National Tuberous Scierosis Association

8000 Corporate Dr, Ste 120 Landover, MD 20785 (800) 225-6872 (301) 459-9888 (301) 459-0394 (fax)

1,2,3,4,5,6,7,8,9,10; blood and tissue donations, audiotapes

Turcot Syndrome

See also: Brain Tumors, Cancer

Turcot Syndrome and Hereditary Medulloblastoma

c/o Dr. Daniel Lasser OB/GYN Columbia Univ College of Physicians 630 W 168th St New York, NY 10032 (212) 305-6784 (212) 305-3869 (fax) ☑ DML1@columbia.edu

Turner Syndrome

See also: Growth Disorders

Turner's Syndrome Society—Canada

7777 Keele St, Fl 2 Concord, ON CAN L4K 1Y7 (800) 465-6744 (905) 660-7766 (905) 660-7450 (fax) 1,2,3,4,5,6,7,10

Turner's Syndrome Society of the US

15500 Wayzata Blvd, #768-214 811 12 Oak Ctr Wayzata, MN 55391 (612) 475-9944 (612) 475-9949 (fax)

1,2,3,4,5,6,7,8,9,10; scholarship program to help girls with Turner syndrome attend national conference

Urea Cycle Disorders

National Urea Cycle Disorders Foundation

PO Box 32 Sayreville, NJ 08872 (800) 386-8233 1,4,6,7,10

Urostomy

See: Ostomy

Urologic Disorders

See: Incontinence, Kidney Disorders

Usher Syndrome

See also: Hearing Impairments, Retinitis Pigmentosa, Visual Impairments

Usher Family Support

c/o Helen Anderson 4918 42nd Ave S Minneapolis, MN 55417 (612) 724-6982 1,4,7,10 **Vascular Malformations**

See also: Hemangioma; Hemorrhagic Telangiectasis, Hereditary; Klippel-Trenaunay Syndrome; Moyamoya Disease; Nevi, Giant Congenital; Sturge-Weber Syndrome

National Vascular Malformations Foundation

8320 Nightingale Dearborn Heights, MI 48127 (313) 274-1243 (voice/fax) 1,4,6, 7

VATER Association

See also: Anorectal Malformations

TEF/VATER Support Network c/o Greg and Terri Burke 15301 Grey Fox Rd Upper Marlboro, MD 20772

(301) 952-6837 1,2,4,5,7,10

Velo-Cardio-Facial Syndrome

See also: Attention Deficit Disorder, Cleft Palate, DiGeorge Syndrome

Velo-Cardio-Facial Syndrome Parent Support Group

110-45 Queens Blvd Forest Hills, NY 11375-5501 (718) 261-8049 (718) 261-7346 (fax) 4,7

Ventilator Use

Citizens for Independence in Living & Breathing

78 Golfwood Hights
Etobiocolce, ON CAN M9P 3M2
(416) 244-2248 (voice/fax)
3,4,6,7,8

International Ventilator Users Networks

5100 Oakland Ave. #206 St Louis, MO 63110 (314) 534-0475 (314) 534-5070 (fax) 1.2.4.7

Vestibular Disorders

See also: Balance Disorders & Dizziness

Vestibular Disorders Association

PO Box 4467 Portland, OR 97208-4467 (800) 837-8428 (503) 229-7705 (503) 228-8665 (TTY) (503) 229-8064 (lax) Est Junder@teleport.com 1.2,3,4,57,10



Visual Impairments

See also: Albinism, Macular Diseases, Retinitis Pigmentosa, Retinoblastoma, Retinopathy of Prematurity, Septo-Optic Dysplasia, Stargardt Disease, Usher Syndrome

American Council of the Blind

1155 15th St NW, Ste 720 Washington, DC 20005 (800) 424-8666 (3–5:30 EST) (202) 467-5081 1,2,6,7,8

American Foundation for the Blind

11 Penn Plaza New York, NY 10001 (800) 232-5463 (212) 507-7600 25 afbinfo@afb.org 1,2,3,7,8,10

American Printing House for the Blind

1839 Frankfort Ave PO Box 6085 Louisville, KY 40206-0085 (800) 223-1839 (502) 895-2405 (502) 895-1509 (fax) 1.2.3

Blind Children's Center

4120 Marathon St Los Angeles, CA 90029 (800) 222-3566 (800) 222-3567 (CA only) 1,2,3,4,7

Blind Children's Fund

2875 Northwind Dr East Lansing, MI 48823-5040 (517) 333-1725 (517) 333-1730 (fax) 1,2,3,4,6,7,8

Canadian National Institute for the Blind

1929 Bayview Ave Toronto, ON CAN M4G 3E8 (416) 486-2500 (416) 480-7417 (TTY) (416) 480-7699 (fax)

Council of Citizens with Low Vision International

5707 Brockton Dr, Ste 302 Indianapolis, IN 46220-5481 (800) 733-2258 (317) 254-1332 (317) 251-6588 (fax) PatPrice@aol.com 1,5,6; scholarships

National Association for Parents of the Visually impaired

PO Box 317 Watertown, MA 02272-0317 (800) 562-6265 (617) 972-7441 (617) 972-7444 (fax) 1,2,4,5,6,7,8,10

National Association for Visually Handicapped

22 W 21st St, 6th Fi New York, NY 10010 (212) 889-3141 (212) 727-2931 (fax) 1,2,7

National Organization of Parents of Blind Children

1800 Johnson St Baltimore, MD 21230 (410) 659-9314 (410) 752-5011 (BBS) (410) 685-5653 (fax) 1,2,3,4,5,6,7,8

Prevent Blindness America

500 E Remington Rd Schaumburg, IL 60173-4557 (800) 331-2020 (708) 843-2020 (708) 843-8458 (fax) 1,2,3,5,6,7,9

Recording for the Blind

20 Roszel Rd Princeton, NJ 08540 (609) 452-0606 (609) 520-7990 (fax) 1,5,7,8,9

The Lighthouse

111 East 59th St New York, NY 10022 (800) 334-5497 (212) 821-9200 (212) 821-9713 (TTY) (212) 821-9705 (fax) 1,2,3,7,8

VIEWS for the Visually Impaired

95 Wareside Rd Etobicoke, ON CAN M9C 3B5 (416) 620-1410 (416) 620-1472 (fax) 1,2,3,4,5,6,7,8,9,10

Vitiligo

National Vitiligo Foundation

PO Box 6337
Tyler, TX 75711
(903) 534-2925
(903) 534-8075 (fax)
23 73071.33@compuserve.com
1,2,5,9.10

Von Hippel-Lindau Syndrome

See also: Ataxia, Balance Disorders & Dizziness, Brain Tumors, Visual Impairments

Von Hippel-Lindau Syndrome Family Alliance 171 Clinton Rd

Brookline, MA 02146 (800) 767-4845 (617) 232-5946 (617) 734-8233 (fax) 1,2,3,4,5,6,7,8,9,10,11 (BBS goes online Jan. 15, 1995; call for details); outpatient clinics in US and other countries

Von Recklinghausen Disease

See: Neurofibromatosis

Weber Syndrome

See: Sturge-Weber Syndrome

Wegener Granulomatosis

See also: Autoimmune Disorders, Granulomatous Disease

Wegener's Granulomatosis Support Group

PO Box 1518 Platte City, MO 64079-1518 (800) 277-9474 (816) 858-4444 (fax) 1.2.3.4.5.6.7.10

Werdnig-Hoffman Disease

See: Spinal Muscular Atrophy

Whistling Face Syndrome

See: Freeman-Sheldon Syndrome

White Matter Disorders

See: Leukodystrophy

Williams Syndrome

See c'so: Autism, Attention Deficit Disorder, Growth Disorders, Heart Disorders, Learning Disabilities

CAWS: Canadian Association for Williams Syndrome

c/o Cathy Wilson PO Box 2115 Vancouver, BC CAN V6B 3T5 (403) 887-5257 1.4,5,6,7,9,10: clinic in Toronto

Williams Syndrome Association

PO Box 297 Clawson, MI 48017-0297 (810) 541-3630 (810) 541-3631 (fax) 1.2.3,4,5,6,7,9,10; regional conferences, summer camp

Wilson's Disease

See: Liver Disorders

Wiskott-Aldrich Syndrome

See: Immune Disorders

Key to Sende

- 1. Periodical/newsletter
- 2. Other publications
- 3. Videos
- 4. Networking/matching
- 5. Local chapters
- 6. National conferences
- 7. Referrals to local resources
- 8. Notional advocacy efforts
- 9. Fund research
- **10.** Maintain registry of individuals with this condition
- 11. Electronic bulletin board (BBS)

Wolf-Hirschhorn Syndrome (4p-)

Wolf-Hirschhorn Syndrome Support Group ภกd Newsletter

5536 Virginia Čt Amherst, OH 44C01 (216) 282-1460 1,4,6

4p- Parent Network

c/o Becky & Tom Richardson 3200 Rivanna Ct Woodbridge, VA 22192 (703) 491-0309 1.4,6,10

Wolf-Parkinson-White Syndrome

See: Growth Disorders

Wolman Syndrome

See: Tay-Sachs Disease

X-Linked Centronuclear Myopathy

See: Myotubular Myopathy

X-Linked Myotubular Myopathy

See: Myotubular Myopathy

Xeroderma Pigmentosum Xeroderma Pigmentosum

Xeroderma Pigmentosun Registry

c/o W. Clark Lambert, M.D.,Ph.D UMD-NJ Medical School Dept of Pathology, Rm C-520 185 S Orange Ave Newark, NJ 07103-2714 (201) 982-6255 (201) 982-7293 (fax) 7,10

Zellweger Syndrome

See: Leukodystrophy



No Longer Alone

Matching organizations help parents find each other

ulie Gordon wanted to help people avoid feeling as she did when she left the hospital with her firstborn child and no answers. Her baby, Jessica, had suffered severe brain damage during delivery and after all the tubes, wires and seizures, was finally placed in her mother's arms with the doctor's proclamation, "Wait and see... We can't fix her."

When Jessica was six, Julie started MUMS, Mothers

United for Moral Support, an international matching organization that now, after 15 years, has more than 5,200 members. Julie and volunteer workers keep a database of children, diagnosed and undiagnosed, to match parents with each other for support.

Like most matching organizations, MUMS began with a phone call. After Jessica was diagnosed with cerebral palsy, Julie got the names of three other mothers whose children also had cerebral palsy. They met for the first

palsy. They met for the first time around Christmas, and talked late into the night.

open-heart surgery.

back with a smile.

[Right] Donny bounces

The group grew by word of mouth, with people coming from a 30-mile radius of Julie's home in Green Bay, Wisconsin. When her database went from index cards to a computer, a national information clearinghouse in South Carolina began to refer people to her from around the country, and the local support group became a nationwide network.

Clearinghouses and groups such as NORD (National Organization for Rare Disorders) and the Alliance for Genetic Support Groups are good resources for information about specific disabilities and referrals to existing groups. However, such groups do not keep track of children who are undiagnosed. And many parents have children with rare conditions, more than one disability or unique family situations like twins or adoption.

Matching groups, both national and international (see sidebar), can help.

Common Ground

Christine Barr and Nancy Bush each have a child with a chromosome 7q deletion. Christine, who lives on Long

Island, New York, and Nancy, who lives in Driggs, Idaho, met through a *Search* letter in *Exceptional Parent* magazine in 1992. That year, they and four other parents started Chromosome Deletion Outreach, a matching group for all conditions caused by chromosomal deletions, additions and inversions. The group has grown from 20 to 275 members.

At first, Christine wanted to talk to a parent who had a child exactly like hers. Instead, she

found a lifelong friend.

Christine's five-year-old daughter, Tyler Marie, is just starting to use a walker, had open-heart surgery and is enrolled in a special school. Nancy's son, Daniel, 10, attends public school and moves, says his mom, "at the speed of light." Both are

non-verbal.

"No two children are exactly the same," said Christine, who sees common experiences shared by all parents of children with disabilities. "We've all been through learning that there is something wrong with our child, the hurt, the disappointment, the fear."

Nancy added, "This group is

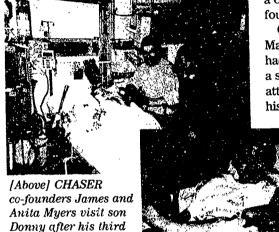
the one place where we can brag about our kids."

Sometimes a support group will start from a match, but some conditions are so rare, there will never be enough parents to form a separate group. "There are more common chromosomal anomalies like Down syndrome and Trisomy 18, but there are also conditions even more rare than chromosome 7 deletions," said Christine. "So, we're kind of all together."

According to Nancy, the group's greatest accomplishment has been getting professionals to refer families to them and to other matching organizations. She hopes for the day when professionals will stop telling parents, "You are the only one," and start telling them, "There is a place you can go."

A Family Affair

Like many other parents of children with disabilities, Anita and James Myers left the hospital after the birth of their second son and entered the information void. Within five hours of a normal birth, their son, Donny, was carted off to intensive care and diagnosed with hypoplastic left heart syndrome. The Myers were given less than 20 minutes to decide on a hospital transfer and





4 £

surgery. They were told not to get their hopes up.

After Donny's surgery, they were not told much of anything.

"We had to become our own detectives," said James, who said often one phone call-even a long shot-can lead to another.

In 1993, when Donny was three years old, the Myers started CHASER—Congenital Heart Anomalies Support. Education and Resources—now an international matching organization for parents of children who have heart disorders along with any additional disabilities.

The Myers live in Swanton, Ohio, a suburb of Toledo.

They call themselves "everyday people" from "smalltown, USA." But, "into the wee hours of the morning." Anita and James are making matches across the globe. sharing resources with a doctor in Israel or a parent in Japan, putting out a newsletter, telephoning, typing or faxing. Their sons Danny, 9, and Donny, now almost 5, help fold and staple. "It's a special family time." said James.

According to Robin Twitty, the Myers have spread the spirit of family far. Her five-year-old daughter, Kaitlin, has CHARGE syndrome, a group of associated disorders which often includes heart defects. Through CHASER,

> Robin has met parents of older children who help to demystify her daughter's future.

"You don't want to talk about the bad things, like how close we came to losing her, but when you do, and someone says 'Yeah, we went through that too,' you really start talking," she said.

Recently, another CHAS-ER mom surprised Robin by driving two and half hours to "drop by" the hospital where Kaitlin was recovering from surgery. "You feel this connection, like they live next door," Robin said.

Someone To Turn To

Many matching organizations across the country and world are run by parents who remember all too well the lonely drives to and from medical centers and hospitals. And, as more matches are made, new support groups continue to form. Joan Weiss, executive director of the Alliance of Genetic Support Groups, sends people free information kits on how to start their own groups. You don't need a college degree, she said, but you do need time. a supportive family, a big kitchen table and, "the ability to look into the future and see how important it is that other people have someone to turn to."

-Andrea Kamens

Matching Resources

The following organizations do parent-to-parent matching and refer parents to local resources. They are in contact with each other and other groups worldwide. Some charge a nominal membership fee. Each listing is followed by a brief description of the conditions with which the group deals.

Association of Birth Defect Children 827 Irma Ave

Orlando, Florida 32803 (800) 313-2232 (answering machine) (407) 245-7035 All birth defects, especially those linked to exposure to environmental toxins such as medication, pesticides, radiation and Agent Orange: new research being done on Gulf War babies.

Association for Neurometabolic Disorders

Cheryl Volk 5223 Brookfield Ln Sylvania, OH 43560-1809 (419) 885-1497 Glactosemia, Maple Syrup Urine disease, Biotinidase, PKU and other metabolic disorders

CHASER: Congenital Heart Anomalies Support, Education and Resources

Anita and James Myers 2112 N Wilkins Rd Swanton, OH 43558 (419) 825-5575 (419) 825-2880 (fax) Congenital heart defects and acquired heart disorders; any disability accompanied by heart prob-

Chromosome Deletion Dutreach

PO Box 532 Center Moriches, NY 11934 (516) 878-3510 or (208) 354-8550 Chromosome deletions, additions and Inversions.

Contact A Family

c/o Harry Marsh 170 Tottenham Court Rd London W1P OHA England (01144) 71-383-5555 All disabilities.

MUMS: Mothers United for Moral Support

c/o Julie Gordon 150 Custer Ct Green Bay, WI 54301-1243 (414) 336-5333 (414) 339-0995 (fax) All disabilities.

National Parent-to-Parent Support and Information System

c/o Kathleen Judd PO Box 907 Blue Ridge, GA 30513 (800) 651-1151 (V/TTY) (706) 632-8822 (V/TTY) (706) 632-8830 (fax) Special health care needs and rare disorders.

Rare Chromosome Disorder Group

Edna Knight Harrow Weald 160 Locket Rd Middlesex England (01144) 81-963-3557 Rare chromosomal disorders.

Search & Respond

c/o Exceptional Parent 209 Harvard St, Ste 303 Brookline, MA 02215 (617) 730-5800 (617) 730-8742 (fax) All disabilities.

Other Resources

The following groups provide information on specific disabilities and refer parents to support groups and other resources. They may provide some matchina.

Alliance of Genetic Support Groups

Joan O. Weiss 35 Wisconsin Circle, Ste 440 Chevy Chase, MD 20815-7015 (800) 336-4363 (301) 654-0171 (fax) Provides free kits on how to start a support group and Information on genetic disorders; no direct parentto-parent matching

Lethbridge Society for Rare Disassas

#2-740 4th Ave S Lethbridge, Alberta T1J ON9 Canada (403) 329-0665 (403) 329-0089 (fax) Provides literature on rare disorders (using the database from NORD) and does parent-to-parent matching within Canada.

NORD: National Organization for Rare Disorders

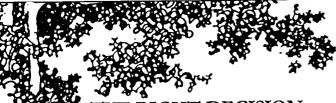
New Fairfield, CT 06812-1783

PO Box 8923

* }

(800) 999-6673 (voice) (203) 746-6927 (TTY) (203) 746-6481 (fax) A confederation of volunteer agencies. Sends literature with information on specific rare disorders and makes referrals to support groups or matching groups. Paid members have access to direct parent networking. Membership \$25/yr.





THE RIGHT DECISION

New England Villages is a private, non-profit residential community nationally recognized for its commitment to personal care and a supportive family-like environment. We provide a full-range of opportunities for your family member in a nonpressured lifestyle.

The Village offers residents single or double rooms in very attractive modern homes or apartments south of Eoston. Our vocational center provides for the satisfaction and dignity of productive employment

in a supervised work setting. A wide range of recreational opportunities and professional support services are available.

A private endowment and minimal dependency on government reimbursement assures stability now and for the future.

Call or write Bryan Efron, Ph.D.. Executive Director for information and a descriptive brochure. A visit to New England Villages may help you make the right decision.



new england villages.inc.

A Model, Supportive Community For Mentally Retarded Adults

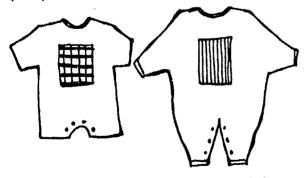
664EP School Street, Pembroke. MA 02359 (617) 293-5461

Circle # 21

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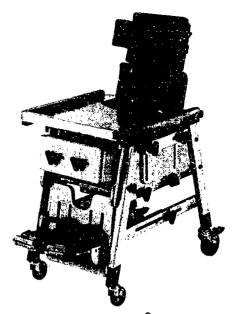
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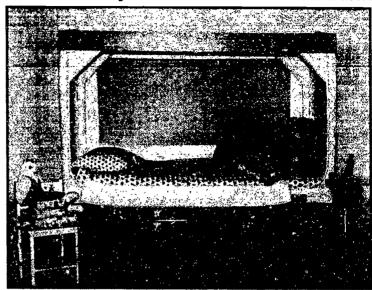
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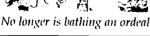
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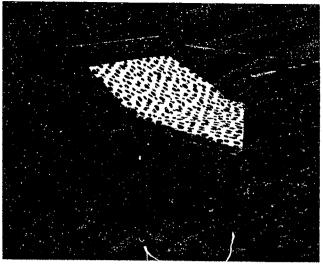


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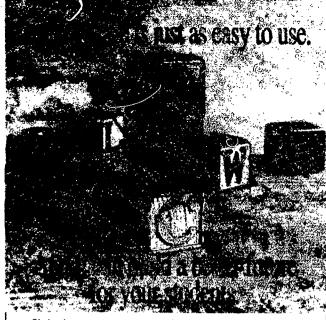
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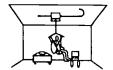
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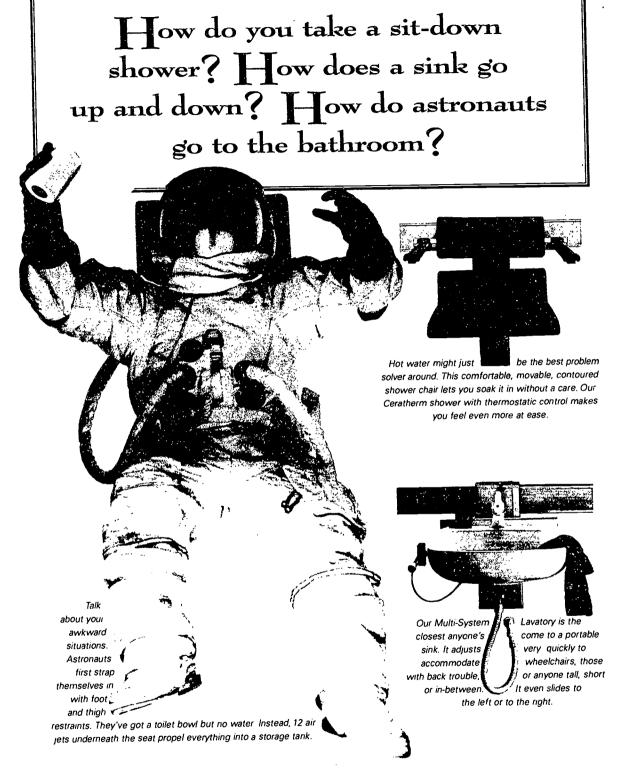
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For more information, contact the National Parent Network on Disabilities (NPND). 1600 Prince St., Ste. 115, Alexandria, VA 22314, (703) 684-6763 (V/TTY), (703) 836-1232 (fax).

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Project STEP: Support & Training for Exceptional Parents

1805 Hayes St. Ste 100 Nashville, TN 37203 (800) 280-STEP (voice) (800) 948-0298 (TTY) (615) 639-0125 (voice) (615) 636-8217 (fax)

TEXAS

Special Kids

PO Box 61628 Houston, TX 77208 (713) 643-9576 (voice) (713) 643-6291 (fax)

Partners Resource Network

1090 Longfellow Dr. Ste B Beaumont, TX 77706-4889 (800) 866-4726 (voice; TX only) (409) 898-4684 (V/TTY) (409) 898-4869 (fax)

Project PODER

2300 West Commerce, Ste 205 San Antonio, 1X 78207 (800) 682-9747 (V/TTY) (210) 222-2637 (V/TTY) (210) 222-2638 (fax)

UTAH

Utah Parent Center

2290 E 4500 S #110 Salt Lake City, UT 84117 (800) 468-1160 (V/TTY; UT only) (8C1) 272-1051 (V/TTY) (801) 272-8907 (fax)

VERMONT

Vermont Parent Information Center

Chace Mill, 1 Mill St, Box A7 Burlington, VT 05401 (800) 639-7170 (V/TTY; VT only) (802, 658-5315 (voice) (802) 658-5395 (fax)

VIRGINIA

PEATC

10340 Democracy Ln, Ste 206 Fairfax, VA 22030 (800): 869-6782 (V/TTY) (703) 691-7826 (V/TTY) (703) 691-8148 (fax)

VIRGIN ISLANDS

Inter-Island Parent Coalition

PO Box 4402 Christiansted St Croix, VI 00802 (809) 778-2275 (voice)

WASHINGTON

Touchstones

6721 51st Ave S Seattle, WA 98118 (206) 721-0867 (V/TTY) (206) 721-2422 (fax)

Washington PAVE

6316 S 12th Tacoma, WA 98465 (800) 572-7368 (V/TTY; WA only) (206) 565-2266 (V/TTY) (206) 566-8052 (fax)

STOMP: Specialized Training of Military Parents 12208 Pacific Hwy SW

Tacoma, WA 98499 (800) 298-3543 (voice) (206) 588-1741 (V/TTY) (206) 984-7520 (fax)

WEST VIRGINIA

West Virginia Parent Training & Information Center

Colonial Village 104 E Main St. #3B Clarksburg, WV 26301 (800) 281-1436 (V/TTY; WV only) (304) 624-1436 (V/TTY) (304) 624-1438 (fax)

WISCONSIN

Parent Education Project of Wisconsin

2192 S 60th St West Allis, WI 53219 (800) 231-8382 (voice; WI only) (414) 328-5520 (voice) (414) 328-5520 (TTY) (414) 328-5520 (fax, call before faxing)

WYOMING

Wyoming Parent Information Center

5 N Lobban Buffalo, WY 82834 (800) 660-9742 (V/TTY; WY only) (307) 684-2277 (V/TTY) (307) 684-5314 (fax)

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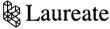
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 Sources on Disabilities (\$15); NARIC Guide to
 Disability and Rohabilitation Periodicals (\$15);
 Americans with Disabilities Act (ADA): A NARIC
 Resource Guide (\$5)

Contact **NARIC** by mail, phone, fax, BBS, or E-mail 8455 Colesville Road, Suite 935, Silver Spring, MD 20910-3319; **800/348-2742 (V/TT)**, 301/588-9284 (V/TT), 301/587-1967 (Fax); 301/589-3563 (BBS); naric@capaccess.org (E-mail)

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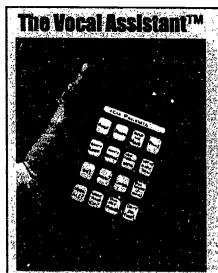
And what do Adam's parents have to say about the new program? "We were pleased with the growth our son exhibited. Heartspring's new summer program met Adam's needs in a diverse way that no other program we've looked at could."

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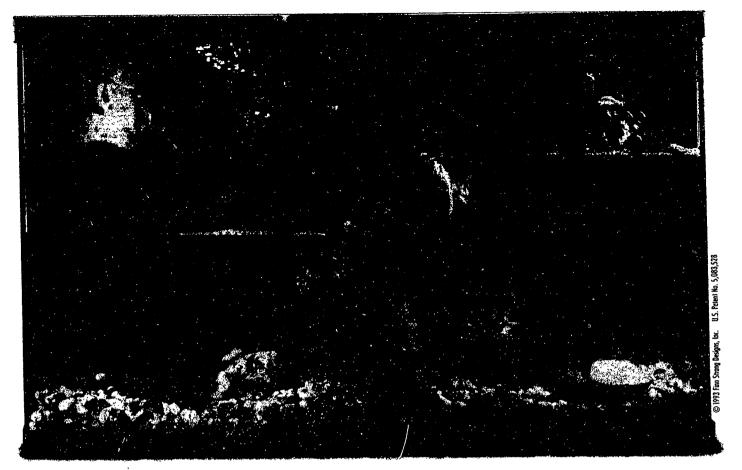
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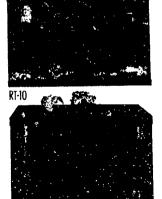
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PARENT-TO PARENT PROGRAMS

arent to Parent (P-P) programs offer a special kind of support to parents who have a child with special needs. Hundreds of active P-P programs in the United States provide emotional and informational support to parents by matching a parent who is referred to the program with an experienced "veteran." parent who has already "been there" and can lend helpful support.

P-P programs originated in Omaha, Nebraska when parents of children with special needs collaborated with a social worker to launch the first Pilot Parents program In the early '70s. The major components of the Pilot Parents model included then—as now—screening and training of veteran parents, carefully made matches between veteran and newly-referred parents and foilow-up support. Many P-P programs also offer a range of other support activities like group meetings for education and support, activities for siblings and extended family members, resource libraries, social events and leadership training.

Annual conference grows

P-P programs and families connect with each other at an international conference every other year. Attendance has grown from fewer than 100 to more than 1,100 parents, children and young adults with disabilities and service providers.

The Eighth International Parent to Parent Conference will be held March 29–April 1, 1996 in Albuquerque, New Mexico. For more information, contact Parents Reaching Out, 1127 University NE, Albuquerque, NM 87102, (505) 842-9045.

The Beach Center

Since 1988, the Beach Center on Families and Disability at the University of Kansas has been conducting research on P-P programs and sharing information and resources. For more information, contact The Beach Center on Families and Disability, University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045, (913) 864-7600 (V/TTY), (913) 864-7605 (fax). Listings in this directory were provided by the Beach Center; please send any corrections directly to them.

Using the Directory

In this directory, P-P programs are categorized by state and alphabetized by town or city within each state listing.

ALABAMA

AIM for Infants

Auburn University Auburn, AL 36849 (205) 844-5943

The Arc of Morgan Cty

2046 Beltline Hwy, Ste 4 Decatur, AL 35601 (205) 355-6192

Parents Support Group

PO Box 1983 Decatur, AL 35602 (205) 350-4502

Special Education Action Committee

PO Box 161724 Mobile, Al. 36616-2274 (800) 222-7322 (AL only)

Alabama Deaf-Blind Multihandicapped Association

PO Box 55 Scottsboro, AL 35768 (205) 259-3158

ARIZONA

Pilot Parent Partnerships

1820 North Kadota Casa Grande, AZ 85222 (602) 836-4830

Pilot Parent Partnerships, Coconino Cty

24 Pine Del Dr Flagstaff, AZ 86001 (602) 774-0187 (After March 1, 1995, 602 area code changes to 520)

Arizona Pilot Parents

PO Box 697 Ganado, AZ 86505 (602) 755-6107

Sharing Down Syndrome East Valley Parent Support Group

425 É Tremaine Gilbert, AZ 85234 (602) 926-8685

Pilot Parent Partnerships, Gila Cty

148 Haskins Rd Globe, AZ 85501 (602) 425-6556

Pilot Parent Partnerships, Mohave Ctv

4140 N Irving Kingman, AZ 86401 (602) 757-5418

Pilot Parent Partnerships, Mohave Cty

2746 Holiday Dr Lake Havasu City, AZ 86403 (602) 855-1915

Pilot Parent Partnerships, Santa Cruz Cty

1810 W Meadow Hills Dr Nogales, AZ 85621 (602) 287-2334

Pilot Parent Partnerships

2150 E Highland, Ste 105 Phoenix, AZ 85016-4720 (602) 468-3001

Prescott Chapter, Arizona Pilot Parents

1907 Cedarwood Cir Prescott, AZ 86301 (602) 468-3001

Pilot Parent Partnerships, Yavapai Cty

2605 Tahosa Dr Prescott, AZ 86301 (602) 445-7994

Pilot Parent Partnerships

5454 Campo Bello Sierra Vista, AZ 95635 (602) 378-6763

Pilot Parent Partnerships, Graham & Greenlee Ctys

PO Box 353 Thatcher, AZ 85552 (602) 428-4731

Pilot Parents of Southern Arizona

2600 N Wyatt Dr Tucson, AZ 85712 (602) 324-3150

Pilot Parent Partnerships, Navajo Cty

PO Box 707 Whiteriver, AZ 85941 (602) 338-4325

Pilot Parent Partnerships, Navajo Cty

PO Box 1148 Winslow, AZ 86047 (602) 289-4323

Pilot Parent Partnerships, Yuma Cty

1321 E 25th Yuma, AZ 85365 (602) 344-0786

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Frank D Lanterman Regional Center

Koch-Young Family Resource Ctr 3440 Wilshire Blvd, Ste 400 Los Angeles, CA 90010 (213) 383-1300

California Association for Parents of the Visually Impaired

PO Box 1126 Los Gatos, CA 95031-1126 (909) 945-5619

Parent to Parent Infant Support Group

Children's Hospital of Orange Cty 455 S Main St Orange, CA 92668 (714) 532-8521

PROUD

PO Box 5822 Orange, CA 92667-5822 (714) 974-6419

Touchstone Support Network

378 Cambridge Ave, Ste K Palo Alto, CA 94306 (415) 328-4495



PHP: The Family Resource Center

3041 Olcott St Santa Clara, CA 95054-3222 (408) 727-5775

Valley Parents Support Group PO Box 5973-272 Sherman Oaks, CA 91413 (818) 902-1616

COLORADO

Child Language Center University of Colorado CB-409, Dept CD-SS Boulder, CO 80309 (303) 492-5375

Peak Parent Center 6055 Lehman Dr. #101 Colorado Springs, CO 80918 (719) 531-9400

Little People of America 7117 E Enclid Dr Englewood, CO 80111 (303) 740-8555

Effective Parents Project 255 Main St Grand Junction, CO 81501 (303) 241-4068

Mile High Down Syndrome Association PO Box 620847

Littleton, CO 80162 (303) 797-1699 **Boulder Cty Spokespeople**

312 Pikes Peak Pl Longmont, CO 80501 (303) 776-3413

CONNECTICUT

Parents Available to Help 42 Brookwood Dr Branford, CT 06405 (203) 488-9640

Cornelia De Lange Syndrome Foundation 60 Dyer Ave Collinsville, CT 06022-1273 (800) 223-8355

Western Connecticut **Association for Human Rights** 11 Lake Ave Extension Danbury, CT 06811 (203) 792-3540

Lower Fairfield Cty Parent to **Parent Network** Arc of Greenwich

50 Glenville St Greenwich, CT 06831 (203) 531-1880

(203) 667-5288

Parent to Parent Network of CT 181 E Cedar St Newington, CT 06111

Oxford Parent Support Group 10 Whitegate Rd Oxford, CT 06478-1501

(203) 888-7326 **Connecticut Traumatic Brain** Injury

1800 Silas Deane Hwy, Ste 224 Rocky Hill, CT 06067 (203) 721-8111

DELAWARE

Parent Information Center Parent to Parent In Delaware 700 Barksdale Rd. Ste 3 Newark, DE 19711 (302) 366-0152

FLORIDA

Gold Coast Down Syndrome Organization 22626 SW 65 Boca Raton, FL 33428 (407) 451-2163

Parent to Parent. Palm Beach Cty 500 NE Spanish River Rd Boca Raton, FL 33404 (407) 842-3213

Family Network on Disabilities 852 St Francis St Brooksville, FL 34601 (904) 544-6433

Family Network on Disabilities, Sumter Cty 5688 Ctv 316A Bushnell, FL 33513 (904) 748-1125

Parent to Parent, Pinellas Cty 1998 Sun Tree Blvd Clearwater, FL 34623 (813) 461-3614

Parent to Parent of Pinellas Cty 1960E Druid Rd Clearwater, FL 34624 (813) 462-9606

Parent to Parent Support Group, Bregard & Central Ctys 1943 Furman Ct

Cocoa, FL 32922 (407) 783-5001

Parent to Parent, **East Volusia Ctv** PO Box 11109 Dayton Beach, FL 32120 (904) 238-3830

Parent to Parent, **West Volusia Cty** 261 Bayou Vista St Debary, FL 32713 (407) 668-5968

Parent Support Group. Nassau Cty

2625 McGregor Blvd Fernandina Beach, FL 32034 (904) 277-1221

Parent Support Group, Hardee & Highlands Ctys

4114 Becton St Frostproof, FL 33843 (813) 284-3087

Parent Support Group, Lake Cty

905 Hickory Ave Fruitland Pk, FL 34731 (904) 326-9082

Heart to Heart of Lee Cty c/o IDEAS 2421 E Mail Dr Ft Myers, FL 33901 (813) 267-9332

Parent to Parent 100 S Andrews Ave Ft Lauderdale, FL 33301 (305) 765-6722

Parent Support Group, Lee Cty 7320 Pebblebeach Rd Ft Myers, FL 33912 (813) 267-9332

Galaxy Center 1901 S 11th St Ft Pierce, FL 34950 (407) 468-5385

Parent to Parent, St Lucie Cty 5006 Citrus Ave Ft Pierce, FL 34982 (407) 465-1786

Parent Support Group University of Florida Box 100296 Gainesville, FL 32610 (904) 392-7078

Parent to Parent, Alachua Cty 2035 NW 18th Ln Gainesville, FL 32605 (904) 375-4636

Parent to Parent, Putnam Cty PO Box 273 Hollister, FL 32147 (904) 328-4107

Family Network on Disabilities, Citrus Cty 922 N Horse Prairie Rd Inverness, FL 34453 (904) 795-7887

Parent Support Group. **Duval Cty** 301 W Bay St Jacksonville, FL 32202 (904) 350-2951

Parent to Parent, Monroe Cty 2824 Fogarty Ave Key West, FL 33040 (305) 294-8973

Parent to Parent, Columbia Cty Rte 7, Box 237 Lake City, FL 32055 (904) 497-2300

Parent to Parent, Polk Cty 1405 Windmere Ave Lakeland, FL 33802 (813) 687-2442

Parent to Parent of Palm Beach 1526 Arabian Dr Loxahatchee, FL 33470 (407) 790-2548

FAME: Families at Mayport are Exceptional 813 Edson Cir W Mayport, FL 32222 (904) 249-1161

Parent to Parent of Miami 5555 SW 93rd Ave Miami, FL 33165 (305) 271-9797

Parent to Parent, Hispanic 9151 SW 6th St Miami, FL 33174 (305) 223-7379

Parent to Parent, Dade Cty 12350 SW 106th St Miami, FL 33186 (305) 666-6511

Parent to Parent. Santa Rosa Cty 5890 Cherokee Rd Milton, FL 32570 (904) 474-5336

Parent to Parent, Pasco Cty 5826 Massachusetts Ave N Port Richey, FL 34652 (813) 841-0684

Parent to Parent, Collier Cty 4230 Mohawk Pl Naples, FL 33962 (813) 774-7761

Parent to Parent, Okaloosa Cty 1136 Sandalwood Cir Niceville, FL 32578 (904) 897-7085

Parent to Parent, Okeechobee Cty 10245 NE 22nd St Okeechobee, FL 34974 (813) 357-0955

Parent Support Group 5031 Myrtle Bay Dr Orlando, FL 32829 (407) 273-2630

PARENT TO PARENT PROGRAMS

Parent Support Group, Escambia Cty

3520 Hopestill Rd Pensacola, FL 32503 (904) 438-9112

Veteran Intensive Care Parents

PO Box 2700. Ste 1N Pensacola, FL 32513-2700 (904) 474-7656

Special Parents

PO Box 15362 Pensacola, FL 32514 (904) 432-4513

Parent Support Group, Taylor Ctv

395 El Camino Perry, FL 32347 (904) 584-3810

Parent Support Group, Charlotte Cty

2410 Lakeview Blvd Port Charlotte, FL 33948 (813) 627-4376

Special Beginnings

1700 S Tamiami Trail Sarasota, FL 34329-3555 (813) 917-2470

Face of Sarasota

PO Box 1424 Sarasota, FL 34230 (813) 955-9250

Parent to Parent, Sarasota & Manatee Ctys

5393 Avenida Del Mare Sarasota, FL 34242 (813) 349-1861

Family Network on Disabilities, Hernando Cty

8131 Rhambouy Rd Spring Hill, FL 34606 (904) 544-6433

Parent to Parent, Leon Cty

1839 Miccosukee Rd, #2A Tallahassee, FL 32308 (904) 877-6968

Family Network on Disabilities

5510 Gray St, Ste 220 Tampa, FL 33624 (800) 825-5736

Parent to Parent, Hillsborough Cty

Mental Health Institute 13301 Bruce B Downs Blvd Tampa, FL 33612-3899 (813) 974-6168

Parent to Parent, Hillsborough Cty

13958 Fletcher Tampa, FL 33612 (813) 626-2600

Family Network on Disabilities, Monroe Cty

165 Pk Ave Taverneir, FL 33070 (305) 852-2592

Parent to Parent Support Group

2945 Elmwood Ct Titusville, FL 32780 (407) 383-0410

Parent to Parent of Indian River

PO Box 6963 Vero Beach, FL 32961 (407) 770-0683

Family Network on Disabilities

PO Box 195747 Winter Springs, FL 32719 (407) 672-4707

Parent to Parent, Pasco Cty

PO Box 1533 Zephyrhills, FL 33539 (813) 783-8111

GEORGIA

Parent to Parent of Georgia

2900 Woodcock Blvd, Ste 240 Atlanta, GA 30341 (404) 451-5484

National Parent to Parent Support and Information System

PO Box 907 Blue Ridge, GA 30513 (706) 632-8822

HAWAII

Hawaii Down Syndrome Congress

419 Keoniana St, #804 Honolulu, HI 96815 (808) 949-1999

IDAHO

Parents Reaching Out to Parents

2195 Ironwood Ct Coeurd'alene, ID 83814 (208) 769-1409

Idaho Autism Association

545 N 100 W Jerome, ID 83338 (208) 324-2927

Parent to Parent

2714 8th Ave Lewiston, ID 83501 (208) 746-8699

Palouse Area Parent to Parent, Whitman, Garfield & Asotin Ctys

103 S Polk Moscow, ID 83843 (208) 882-9338

ILLINOIS

Archway Services for Children

1108 W Willow Carbondale, IL 62959 (618) 549-4442

Developmental Services Center

1304 W Bradley Champaign, IL 61821 (217) 359-0287

Illinois Next Steps, Parents Reaching Parents

100 W Randolph, Ste 8-100 Chicago, IL 60601 (800) 275-3677 (IL only)

Family Support Project

20 E Jackson Blvd, Rm 900 Chicago, IL 60604 (312) 939-3513

South Cook Cty Parent to Parent Program

Greater Interagency Council 800 Governor's Hwy Flossmoor, IL 60422 (708) 957-7100

National Association for Down Syndrome

PO Box 4542 Oak Brook, IL 60522-4542 (708) 325-9112

INDIANA

First Step Early Intervention PO Box 98

Batesville, IN 47006-0098 (812) 934-4528

Connection for Special Kids

692 ESR 218 Berne, IN 46711 (219) 589-3543

Down Syndrome Support Association

10792 Downing St Carmel, IN 46033-3869 (317) 574-9757

Neo Fight

4363 Idlewild Ln Carmel, IN 46033 (317) 843-0850

Abilities Services

PO Box 808 1237 Concord Rd Crawfordsville, IN 47933 (317) 362-4020

Down Syndrome Association of NW Indiana

2927 Jewett Ave Highland, IN 46322 (219) 836-3656

Indiana Parent Information Network

4755 Kingsway Dr Indianapolis, IN 46205 (317) 257-8683

Special Education Parents Advisory Council

202 W 47th St Indianapolis, IN 46208-3510 (317) 257-2962

First Steps

PO Box 6449 Lafayette, IN 47903-6449 (317) 423-5531

Roots-Wings Parent Involvement

1642 W McLain Scottsburg, IN 47170 (812) 752-4892

Parent Family, Alumni Support

615 N Michigan St South Bend, IN 46601 (219) 284-7308

Knox Cty Advocates for Special Kids

1806 Indiana Ave Vincennes, IN 47591 (812) 882-0375

IOWA

Family Educator Connection Program

3706 Cedar Heights Dr Cedar Falls, IA 50613 (319) 273-8265

Pilot Parents, The Arc of East Central Iowa

136 36th Dr SE, Ste A-5 Cedar Rapids, IA 52403 (319) 365-0487

Union Cty Pilot Parents

PO Box 57 Creston, IA 50801 (515) 782-5128

Autism Society of the Quad Cities

4712 Belle Ave Davenport, IA 52807 (319) 359-5414

Parent-Educator Connection

MPRRC, Drake University Des Moines, IA 50311 (515) 271-3936

Special Care Parents, Polk Cty

PO Box 938 Des Moines, iA 50304 (515) 279-7810

Iowa Pilot Parents

33 N 12th St, PO Box 1151 Fort Dodge, IA 50501 (515) 576-5870



Parent Educator Connection

1382 4th Ave NE Sioux Center, IA 51250 (712) 722-4374

Parent to Parent Support Group

2320 S Olive Sioux City, IA 51106 (712) 274-2838

KANSAS

Parent to Parent of Butler Cty 1432 W Olive

1432 W Olive El Dorado, KS 67042 (316) 321-3274

Parent to Parent of Flint Hills

1722 Yucca Ln Emporia, KS 66801 (316) 342-6954

Parent to Parent of Garden City

116 E Chestnut, Ste 103 Garden City, KS 67846 (316) 226-6364

Parent to Parent of NW Kansas

Box 15 Gem, KS 67734 (913) 462-6857

Parent to Parent, Wyandotte Cty

2234 Garfield Ave Kansas City, KS 66104 (913) 342-9833

Parent to Parent, Douglas Cty

Rte 3, Box 56 Lawrence, KS 66044 (913) 832-1430

Parents Who Care

3312 Effingham Manhattan, KS 66502 (913) 776-9268

Parent to Parent

30 Oak St Ct Medicine Lodge, KS 67104 (316) 886-3590

Parent to Parent of NE Kansas

P0 Box 488, 404 Pk Oskaloosa, KS 66066 (913) 863-3257

Parent to Parent of SE Kansas

3118 Corning Parsons, KS 67357 (316) 421-6550

Parent to Parent, Johnson Cty

10201 Horton Shawnee Mission, KS 66207 (913) 967-7677

Rubinstein-Taybi Syndrome Parent Group

PO Box 146 Smith Center, KS 66967 (913) 697-2984

Families Together

501 Jackson St, Ste 400 Topeka, KS 66603 (913) 233-4777

Parent to Parent

2218 Wilmington Ct Topeka, KS 66606 (913) 235-9680

Parent to Parent, Sedgwick Ctv

2312 S Meridian, Ste 102 Wichita, KS 67213 (316) 945-7747

KENTUCKY

Parents Confronting Dual Sensory Impairments

PO Box 60 Fordsville, KY 42343 (502) 276-3360

Parents Outreach

1146 S Third St Louisville, KY 40203 (502) 584-1239

Down Syndrome of Louisville

PO Box 22552 Louisville, KY 40252 (502) 425-0784

LOUISIANA

Parent Training Program

PO Box 94064 Baton Rouge, LA 70804 (504) 763-3588

Louisiana Rett Syndrome Foundation

7629 Sailfish Dr Lake Charles, LA 70605 (318) 474-5727

Parent to Parent of Louisiana

Family Support Program Children's Hospital 200 Henry Clay New Orleans, LA 70118 (504) 896-9268

Concerned Parents For Students

1022 Gulf Ln Sulphur, LA 70663 (318) 528 2191

MAINE

Maine Parent Federation

PO Box 2067 Augusta, ME 04338-2067 (207) 582 2504

Parent Program

11 Maple St Reckland, ME 04841 (207) 594-8474

York Cty Parent Awareness

150 Main St, Midtown Mall Sanford, ME 04073 (207) 324 2337

MARYLAND

Maryland Infants & Toddlers Program

1 Market Ctr, Ste 304 Baltimore, MD 21201-3446 (410) 333 8100

National Organization of Parents of Blind Children

1800 Johnson St Baltimore, MD 21230 (410) 659-9314

Learning Disabilities Association of Metropolitan Baltimore

76 Cranbrook Rd, Ste 299 Cockeysville, MD 21030 (410) 821-7010

Epilepsy Foundation of America

4351 Garden City Dr Landover, MD 20785 (301) 459-3700

MASSACHUSETTS

Greater Boston Parent to Parent

1505 Commonwealth Ave Boston, MA 02135 (617) 783-3900

Birth Defects Service

Children's Hospital 300 Longwood Ave Boston, MA 02115 (617) 735-6394

Parent Peer Support Group National Tay-Sachs & Allied Diseases Association

2001 Beacon St Brookline, MA 02146 (617) 277-4463

Massachusetts Down Syndrome Congress

P0 Box 866 Melrose, MA 02176 (617) 742-4440

Family Ties of Massachusetts

Dept of Public Health 180 Beaman St West Boylston, MA 01583 (508) 792-7880

MICHIGAN

TRENDS

P0 Box 1996 Holland, MI 49422-1996 (616) 392-6307

Kidpower

Autism Society of Michigan 809 Center St, Ste 8A Lansing, MI 48904 (517) 487-9260

67

MINNESOTA

Pilot Parents of Northeastern Minnesota

201 Ordean Bldg Duluth, MN 55802 (218) 726-4725

The Windmill Project

W Central ECSU 1001 E Mount Faith Fergus Falls, MN 56537 (218) 739-3273

People To People Disability Aware

Rte 2, Box 145 Owatonna, MN 55060-9624 (507) 451-4585

Family Llason Project

903 W Center St, Rm 160 Rochester, MN 55902 (507) 287-2032

Midstate Pilot Parents

PO Box 1536 St Cloud, MN 56302 (612) 253-6844

Pilot Parents

425 Etna St, #35 St Paul, MN 55106 (612) 778-0727

Parents for Parents

280 N Smith Ave, Ste 245 St Paul, MN 55102 (612) 220-6731

Veteran Parents

280 N Smith Ave, Ste 245 St Paul, MN 55102 (612) 220-6731

MISSISSIPPI

Mississippi Gulf Coast Exceptional Parents

PO Box 271 Hurley, MS 39555 (601) 588-2260

MISSOUR!

Parents Helping Parents

1702 E Laharpe Kirksville, MO 63501 (800) 621-6082

Pilot Parents Program

PO Box 10984 Springfield, MO 65808-0984 (417) 831-0648

Positive Parenting Partners

United Services 4140 Old Mill Pkwy St Peters, MO 63376 (314) 926-2700

Keeping Individuals With Developmental Disabilities Serviced

PO Box 1308 Warsaw, MO 65355 (816) 438-6990

MONTANA

Parents, Let's Unite For Kids 1500 N 30th St Billings, MT 59101-0298 (406) 657-2055

Quality Life Concepts

600 6th St, NW PO Box 2506 Great Falls, MT 59403 (406) 452-9531

Parents of Children With Special Needs

University of Montana School of Education Missoula, MT 59812 (406) 243-5344

NEBRASKA

Parent Assistance Network 310 W 24th Kearney, NE 68847 (308) 237-6025

Parents Encouraging Parents Nebraska Dept of Education 301 Centennial Mall S

Lincoln, NE 68509 (402) 471-2471

Pilot Parents Program 215 Centennial Mall S, #410 Lincoln, NE 68508 (402) 477-6925

Nebraska Family Support Network

215 Centennial Mall S Lincoln, NE 68508 (402) 477-2992

Pilot Parents Program, Greater Omaha

3610 Dodge St Omaha, NE 68131 (402) 346-5220

NEVADA

Nevada Association for the Handicapped 6200 W Oakey Las Vegas, NV 89102

Las Vegas, NV 89102 (702) 870-7050

Nevada Parent Network College of Education/278 Reno. NV 89557-0082 (702) 784 4921

NEW HAMPSHIRE

Parent to Parent of Northern New Hampshire 69 Willard St

69 Willard St Berlin, NH 03570 (603) 752-8531 Upper Valley Support Group

PO Box 622 Hanover, NH 03755 (603) 448-6311

Parent to Parent of New Hampshire

PO Box 622 Hanover, NH 03755 (603) 448-6393

Parent to Parent

32 SW Hwy, Ste 22 Merrimack, NH 03054 (603) 882-6333

NEW JERSEY

Down Syndrome Parent to Parent

7 Regent St Livingston, NJ 07039 (201) 535-1181

PEP: Parents Encouraging Parents

The Arc-Morris Chapter PO Box 123 Morris Plains, NJ 07950 (201) 326-9750

Sturge-Weber Foundation PO Box 418

Mt Freedom, NJ 07970 (201) 895-4445

National Urea Cycle Disorders Foundation

PO Box 32 Sayreville, NJ 08872 (800) 386-8233

Family Support Clearinghouse 2150 Hwy 35, Ste 207C Sea Girt, NJ 08750 (908) 974-1144

NEW MEXICO

Parents Reaching Out 1127 University, NE Albuquerque, NM 87102 (505) 842-9045

NEW YORK

Headway for Brain Injured 856 Ridge Rd Buffalo, NY 14118 (716) 822-2261

Parent to Parent, Western NY Parent Network of NY State 432 Delaware Ave Buffalo, NY 14202 (800) 305-8813

Prader-Willi Forum 40 Holly Ln Roslyn Heights, NY 11577 (800) 358-0682

Parents of Special Children 2C Tower Dr Fulton, NY 13069 (315) 598-7672 The MPS Society

17 Kraemer St Hicksville, NY 11801 (516) 931-6338

Parent to Parent, South Central NY

Family Resource Network 16 Ford Ave, Box 233 Oneonta. NY 13820 (800) 305-8814

Parent Assistance Committee on Down Syndrome

208 Lafayette Ave Peekskill, NY 10566 (914) 739 4085

Parent to Parent of New York State

Balltown and Consaul Rds Schenectady, NY 12304 (800) 305-8817

Parent to Parent, North Central NY

Exceptional Family Resources 731 James St, Ste 311 Syracuse, NY 13203 (800) 305-8815

Parent to Parent, Hudson Valley

Family Connection/WIHD Cedarwood Hall Valhalla, NY 10595 (800) 305-8816

Parent to Parent 239 Champion Ave Webster, NY 14580

(716) 265-3778

NORTH CAROLINA

Parent to Parent

Rte 2, Box 178A Angier, NC 27501 (919) 639-0172

Parents Reaching Out to Parents

PO Box 638 Biscoe, NC 27209 (910) 428-9944

Parent to Parent/Family Support

Appalachian State University Edwin Duncan Hall Boone, NC 28608 (704) 262-6089

Parent Support Group 63 N Canton Rd Canton. NC 28716 (704) 452-4397

University Of North Carolina School of Deutistry Chapel Hill, NC 27599 (919) 966-2275 Family Support Network of North Carolina

UNC-Chapel Hill, CB#7340 Chapel Hill, NC 27599 (919) 966-2841

Family Support Network of Catawba Cty Rte 2, Box 396

Rte 2, Box 396 Conover, NC 28613 (707) 326-5953

Family Support Network of Orange, Durham & Chatham Ctys

115 Market St, Ste 201 Durham, NC 27701 (919) 560-5600

Family Support of the Albemarle Area 1601 Forest Dr

1601 Forest Dr Elizabeth City, NC 27909 (919) 338-6987

Reaching Out Family Support Group

609-A Murchison Rd Fayetteville, NC 28306 (910) 424-7669

Parent to Parent Support Fort Bragg & Pope Families 8 Avellino Rd Fort Bragg, NC 28307 (910) 960-2558

Family Support Network 1623 N Webb St School Gastonia, NC 28054 (704) 854-4839

Family Support Network 719 E Ash St Goldsboro, NC 27530 (919) 580-0330

Family Support Network of Greater Greensboro 801 Green Valley Rd Greensboro, NC 27408

(910) 574-6507

Family Support Network of Eastern North Carolina Irons Bldg, ECU Campus

Greenville, NC 27858 (919) 328-4494 Parents Resource Organization

142 Cemetery Rd Mocksville, NC 27028 (910) 998-3311

Family Support Network/Hope Network Western Carolina Ctr

Western Carolina Ctr 300 Enola Rd Morganton, NC 28655 (704) 433-2661



Family Support Network of the Neuse Area

1405 S Glenburnie Rd New Bern, NC 28562 (919) 514-4770

Parents Encouraging Parents

PO Box 1318 Pisgah Foresi, NC 27605 (704) 884-5649

Family Support Network, Wake Cty

319 Chapanoke Rd. Ste 101 Raleigh, NC 27603 (919) 662-4600

Child and Adolescent Network

4904 Watersedge Dr, Ste 152 Raleigh, NC 27606 (919) 851-0063

Child and Family Services Branch

Division of MH/DD/SAS 325 N Salisbury St, Rm 517 Raleigh, NC 27603 (319) 733-0598

Caring Parents

1506 Laurel St Roanoke Rapids, NC 27870 (919) 535-5887

Family Support Network

Rt 11, Box 369A Statesville, NC 28677 (704) 876-4621

Family Support Network of SE North Carolina

1804 Chestnut St Wilmington, NC 28405 910) 763-3331

Parents Together

4505 Shattalon Dr Winston-Salem, NC 27106 (910) 924-5301

OHIO

Down Syndrome Association of Greater Cincinnati

1821 Summit Rd, Ste 102 Circinnati, 0H 45237 (513) 761-5400

Ohio Protection & Advocacy Association

4030 Mt Carmel/Tobasco. Ste 214 Cincinnati, 04 45255 (513) 528-4690

Ohio Protection & Advocacy **Association**

5039 Brookpark Rd Cleveland, OH 44134 (216) 398-5501

The Family Information Network

246 N High St, 5th Fl Columbus, OH 43266 (614) 644-8389

Ohio Head Injury Association

1335 Dublin Rd, Ste 50A mbus, OH 43215 (C141 431-7100

Celebrating Families of Children

16 Vassar Dr Dayton, OH 45406 (513) 275-0990

Special Needs Information Center

832 Shannon Rd Girard, OH 44420 (216) 545-2837

Miami Valley Down Syndrome Association

1444 Beaver Creek Ln Kettering, OH 45429 (513) 294-1240

Family Information Network of **NW Ohio**

1 Stranahan Sq. #540 Toledo, OH 43604 (419) 242-9587

OREGON

The Arc of Lane Ctv

Parent Network 45 W Broadway, Ste 205 Eugene, OR 97401 (503) 343-5256

Parent Support Group

2825 Barnett Rd Medford, OR 97504 (503) 770-4233

Oregon Cope Project

999 Locust St NE Salem, OR 97303-5299 (503) 373-7477

PENNSYLVANIA

Brain Injury Support Group

595 W State St Dovlestown, PA 18901 (215) 345-2634

Parent Support Center

252 Waterford St Edinboro, PA 16412 (814) 734-5610

Westmoreland Ctv Parent to Parent

Rd 12 Box 179 Donchoe Rd Greensburg, PA 15601 112) 837-8159

Down Syndrome Support Group of Lancaster Cty

c/o S. June Smith Ctr 25 NW End Ave Lancaster, PA 17603 (717) 299-4829

Charcot-Marie-Tooth Association

601 Upland Ave Upland, PA 19015 (800) 606-2682

RHODE ISLAND

Parents Reaching Out

1 Simmons Rd Barrington, RI 02806 (401) 245-5241

Down Syndrome Society of Rhode Island

99 Bald Hill Rd Cranston, R! ()2920 (401) 463-5/51

Parent Training Program, Special Education

22 Hayes St Providence, RI 02908 (401) 277-3505

Central Region Early Intervention Program J Arthur Mem Ctr

250 Commonwealth Warwick, RI 02886 (401) 823-1731

SOUTH CAROLINA

Family Connection of South Carolina

2712 Middleburg Dr Columbia, SC 29204 (803) 252-0914

Parents Reaching Out, **Parents of South Carolina**

2712 Middleburg Dr, Ste 102 Columbia, SC 29204 (803) 779-3859

SOUTH DAKOTA

Parent to Parent

2501 W 26th St Sioux Falls, SD 57105-2498 (605) 334-3119

TERNESSEE

Parent to Parent

312 8th Ave. 10th FI Nashville, TN 37247 (615) 741-0361

TEXAS

Parent Case Management Program

4601 Hartford Abilene, TX 79605 (915) 691-7232

Pilot Parent

The Arc 2818 San Gabriel Austin, 1X 78/05-3598 (512) 476-7044

Partners Resource Network

1090 Longfellow, Ste B Beaumont, TX 77706-4889 (409) 398-4684

Parent to Parent

PO Box 113162 Carrollton, TX 75011-3163 (214) 994-3484

Tarrant Cly Society for Hearing Impaired Infants and Youth

6416 Canvon Cir Fort Worth, TX 76133 (817) 346-0421

Parent to Parent

307 Peterson Royse City, TX 75089 (214) 636-9604

Parent Case Management Program of West Taxas Rehabilitation Centers

3001 S Jackson San Angelo, TX 76904 (915) 949-9535

UTAH

Parent to Parent

50 N Medical Dr, Rm 2553 Salt Lake City, UT 84132 (801) 581-2098

Graduate Parents

100 N Medical Dr Salt Lake City, UT 84113-1100 (801) 588-3899

HOPE: A Parent to Parent Network

2290 E 4500 S, Ste 110 Salt Lake City, UT 84117 (801) 272-1051

VERMONT

Vermont Family Resource Consultants

UAP of Vermont 499C Waterman Bldg Burlington, VT 05405 (802) 656-4031

Parent to Parent of Vermont

1 Main St, 69 Champlain Mill Winooski, VT 05404 (802) 655-5290

Virginia

Culpepper Area Parent to Parent

Rte 2, Box 263J Amissville, VA 22002 (703) 937-2155

Parent to Parent of Alexandria 4729 N 20th St

Artington, VA 22207 (703) 524-8222

SW Virginia Parent to Parent

Drawer II Big Stone Gap, VA 24219 (703) 523-0682

Charlottesville Parent to Parent

Rte 2, Box 402A Crozet, VA 23932 (804) 973-2247

Prince William Parent to Parent

15077 Lindenberry Ln Dumfries, VA 22026 (703) 691-7826

Parent to Parent of Northern Virginia

PEATC 10340 Democracy Ln, Ste 206 Fairfax, VA 22030 (703) 691-7826

Parent to Parent of Hampton Roads

1600B 5th St Bethel Manor Hampton, VA 23655 (804) 865-0463

Harrisonburg-Rockingham Parent to Parent

1251 Smithland Rd Harrisonburg, VA 22801 (703) 433 5821

Twin Cty/Galax Parent to Parent

PO Box 931 Hillsville, VA 24343 (703) 236-6585

Parent to Parent, Whythe Cty

Rte 1, Box 50 Ivanhoe, VA 24350 (703) 699-6341

Parent to Parent of Central Virginia

Arc of Central Virginia 1264 Krise Cir Lynchburg, VA 24503

Fairfax Cty Parent to Parent

10509 Adel Rd Oakton, VA 22124 (703) 281-7113

Parent to Parent of Southside Virginia

20 W Bank St, Ste C Petersburg, VA 23803 (804) 862-8049

Parent to Parent of Southside Virginia

Crater District Infant Intervention Program 2008 Wakefield Ave Petersburg, VA 23805 (804) 862-9940

Parent to Parent

1518 Willow Lawn Dr Richmond, VA 23230 (804) 282-4255

Richmond Parent to Parent

1540 Honey Grove Dr Richmond, VA 23229 (804) 270-1883

Parent to Parent of Roanoke

3857 Hummingbird Ln Roanoke, VA 24018 (703) 989-5042

Parent to Parent, Roanoke

3020 Mansfield St Roanoke, VA 24012 (703) 366-3551

Parents of Children with Down Syndrome

6111 Roxbury Ave Springfield, VA 22152 (703) 451-6328

Raddanock Parent to Parent

2015 Buoy Dr Stafford, VA 22554 (703) 659-4957

Loudon Parent to Parent

104 Country Rd Sterling, VA 20165 (703) 406-7804

Tidewater Area Parent to Parent

707 Gittings St, Ste 170 Suffolk, VA 23434 (804) 539-8616

Virginia Beach Parent to Parent

405 W Farmington Rd Virginia Beach, VA 23454 (804) 340-1954

WASHINGTON

Grays Harbor Parent to Parent

117 E 3rd, PO Box 1827 Aberdeen, WA 98520 (206) 533-5100

Parent to Parent, Whatcom Cty

1111 Cornwall Ave, Ste 205 Bellingham, WA 98225 (206) 966-7932

Parent to Parent

The Arc of Kitsap Cly 3243 N Perry Ave Bremerton, WA 98310 (206) 377-3473

Parent to Parent Support Program

156 NW Prindle Chehalis, WA 98532 (206) 748-4359

Parent to Parent, Snohomish Cty

2531 Wetmore Everett, WA 98201-2919 (206) 258-2459

Parent to Parent Support Program

The Arc of Cowlitz Valley 1129 Broadway Longview, WA 98632 (206) 532-5494

Parent to Parent, Grant, Adams & Lincoln Ctys

903 W 3rd Moses Lake, WA 98837 (509) 765-3686

Parent to Parent Support Program, Skagit Cty

PO Box 1833 Mc art Vernon, WA 98273 (206) 757-7048

Parent to Parent, Thurston Cty

1703 E State Ave Olympia, WA 98506 (206) 352-1126

Parent to Parent

PO Box 3051 Omak, WA 98841 (509) 826-0716

Parent to Parent Support Program, Ciallam Cty

2039 W 10th St Port Angeles, WA 98363 (206) 457-1282

Parent to Parent Support Program, Benton & Franklin Ctys

767 Williams Blvd Richland, WA 99352 (509) 943-2908

The Cleft Connection

110 Prefontaine PI S, Ste 500 Seattle, WA 98104 (206) 296-4665

Parent to Parent Programs The Arc of King Cty

10550 Lake City Way NE, Ste A Seattle, WA 98125-7752 (206) 948-7322

King Cty Parent to Parent

10550 Lake City Wy NE, Ste A Seattle, WA 98125-7752 (206) 364-4645

Parent to Parent Support Programs, Mason Cty

428 W Birch Shelton, WA 98584 (206) 426-1005

Parent to Parent Support Program, Spokane Cty

W 127 Boone Ave Spokane. WA 99201 (509) 244-4499

Parent to Parent

12208 Pacific Hwy SW Tacoma, WA 98499 (206) 588-1741

Parent to Parent Support Program

Arc of Clark Cty PO Box 2608 Vancouver, WA 98668 (206) 254-1562

Parent to Parent/De Padre a Padre, Walla Walla & Columbia Ctys

PO Box 1595 Walla Walla, WA 99362 (509) 527-3278

Parent to Parent, Chelan & Douglas Ctys

PO Box 1 Wenatchee, WA 98807 (509) 782-4476

Parent to Parent Support Program

603 S 18th Ave Yakima, WA 98902 (509) 452-1382

WEST VIRGINIA

Autism Services Center

Prichard Bldg, 9th FI 305 9th St Huntington, WV 25710-0507 (304) 525-8014

WISCONSIN

Pilot Parents

Rte 2, Box 434 Ashland, WI 54806 (715) 682-2671

Brown Cty Arc

P0 Box 12770 Green Bay, WI 54307-2770 (414) 498-2599

DEAF

PO Box 23825 Green Bay, WI 54305-5825 (414) 437-7531

MUMS National Parent to Parent

150 Custer Ct Green Bay, WI 54301-1243 (414) 336-5333

SW Wisconsin Parents of Down Syndrome Persons

18716 W Mound Rd Platteville, WI 53818 (608) 348-8906

Racine Parent Support

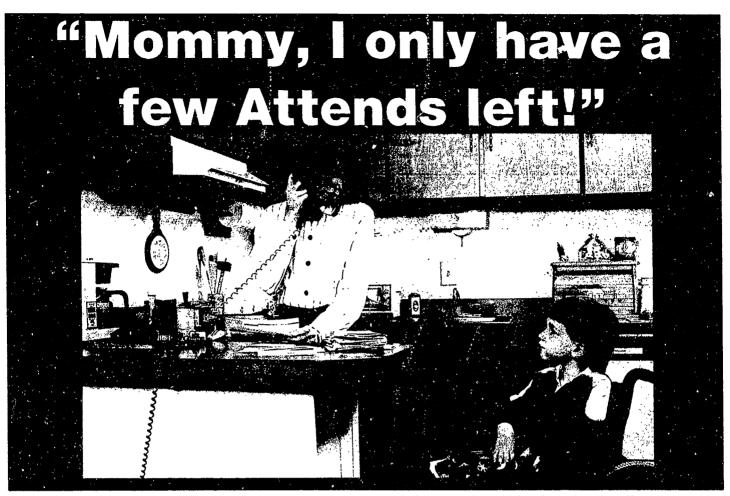
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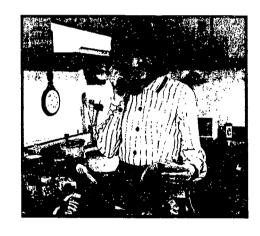
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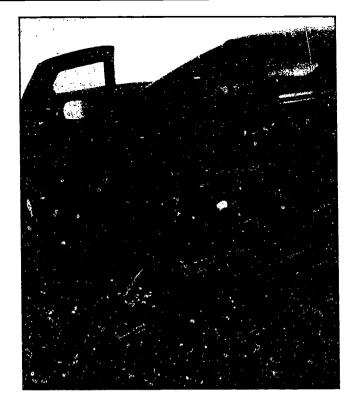
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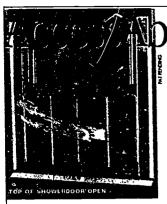
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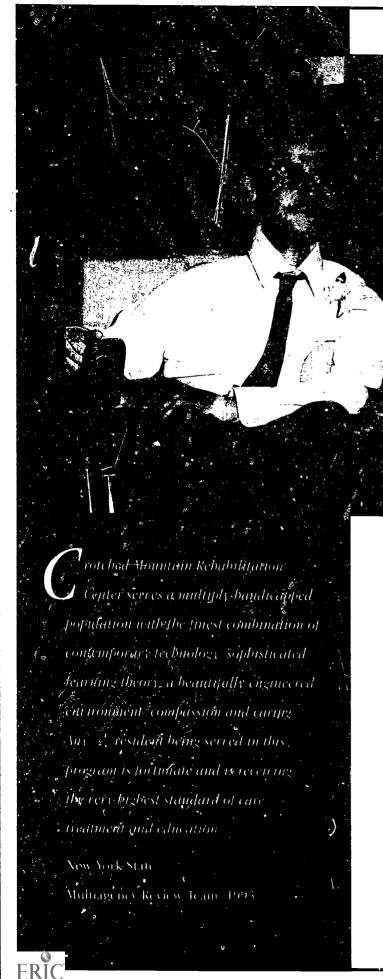
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HAWAII

Aloha Special Technology Access Center

1750 Kalakaua Ave #1008 Honolulu, Hl 96826-3725 (808) 955-4464 (voice/fax) sachi@aol.com 1,2,3,4,5,6,7,8,9,10,11,12,13, 14,15,16,20

ILLINOIS

Northern Illinois Center for Adaptive Technology

3615 Louisiana Rd Rockford, IL 61108-6195 (815) 229-2163 (voice) (815) 229-2120 (fax) Sailca@aol.com

M ilca@aol.com 1,2,3,4,5,6,7,8,9,10,11,12,13, 15,17,18,19.20 TECHNOLOGY



Technical Aids & Assistance for Persons with Disabilities Center

1950 W Roosevelt Chicago, IL 60508 (312) 421-3373 (V/TTY) (312) 421-3464 (fax) 🖄 tal fronter@aoi.com 1 2,3,11,12,13,15.19

INDIANA

Assistive Technology Training and Information Center

3354 Pine Hill Dr PO Box 2441 Vincennes, IN 47591 (800) 962-8842 (V/TTY) (812) 882-1128 (fax) inattic1@aol com 1,2,4,5,6,7,8,9,10,11,12,13,15, 18 19

KANSAS

Technology Resources and Solutions for People

3023 Canterbury Rd and 1710 W Schilling Rd Salina, KS 67401 (913) 827-9383 (V/TTY) (913) 827-0301 (V/TTY) (913) 827-5446 (f^x) ★ trspks@acl.com 1,4.5.7,8,11,12,13,14,15.16.18

KENTICKY

Blue Grass Technology Center

169 N Limestone Lexington, KY 40507 (606) 255-9951 (V/TTY) (606) 255-0059 (fax) 1,2,3,4.6,7.8,9.10.11.12.14.15. .8,19; supported employment services for rural Kentucky

Enabling Technologies of Kentuckiana

Louisviile Free Public Library 301 York St Louisville, KY 40203-2257 (502) 574-1637 (voice) (502) 574-1674 (TTY) (502) 582-2448 (fax) 1,2,3,6,7,8,9,11,12,13.14,15,16, 17,18,19,20

SpeciaLink

36 W 5th St Covington, KY 41011 (606) 491-2464 (voice/fax) spclinkky@aol.com

1,2,3.4,5,6,7,8,9,10.11,12,13, 14.15.16.19.20: software development, regional center for SW Ohio, N Kentucky & SE Indiana

LOUISIANA

CATER-Center for Adaptive Technology and Educational Resources

731 Park Ave Mandeville, LA 70448-4918 (504) 626-7088 (voice/fax) 🖄 caterla@aol.com 1,2,4,5,7,9,10,11,12,13,15,18,20

MARYLAND

Learning Independence **Through Computers**

28 E Ostend Sc Baltimore, MD 21230 (410) 659-5462 (voice) (410) 659-5469 (TiY) (410) 659-5472 (fax) incr.d@aol.com 1,2,5,10,12,13,15,17,19,20

MASSACHUSETTS

Massachusetts Special **Technology Access Genter**

12 Mudge Way 1-6 Bedford, MA 01730-2138 (617) 275-2446 (voice) 1.2.5,7,8.9,10,11,12,13,14,15, 16.19.20

MICHIGAN

Living & Learning Resource Centre

Physically Impaired Association of Michigan 601 W Maple St Lansing, MI 48906-5038 (517) 487-0883 (V/TTY) (517) 487-1605 (fax) Ircni@aol.com 1,2,3,5,6.8,9,11,12,13,14,15,19

MINNESOTA

PACER Computer Resource Center

4826 Chicago Ave S Minneapolis, MN 55417-1098 (612) 827-2966 (V/TTY) (612) 827-3065 (fax)

1,3,4,5,6,8,9.11,12,13,15,20

MISSOURI

Technology Access Center

12110 Clayton Rd St Louis, MO 63131-2599 (314) 569-8404 (voice) (314) 569-8409 (TTY) (314) 993-5937 (fax) mostltac@aol.com 1.4,5,6,9,12,13,15,19.20

MONTANA

Parents, Let's Unite for Kids

MSU Billings SPED267 1500 N 30th St Billings, MT 59101-0298 (406) 657-2055 (V/TTY) (406) 657-2061 (fax) ₽ plukmt@aol.com

1,2,3,4,5,6,7,8,9,10,11 12,13, 15, 16, 17, 18, 19, 20; book-lending library MedLine searches, database, Parent Training Center

NEW JERSEY

Center for Enabling Technology

622 Route 10 W. #22B Whippany, NJ 07981-0272 (201) 428-1455 (voice) cetni@aol.com

1,2,3,12,13,15,16,17,20, open resource times

Computer Center for People with disAbilities

35 Haddon Ave Shrewsbury, NJ 07702-4007 (908) 747-5310 (voice) (908) 747-5936 (fax) 🖄 ccdari@aol.com 1.2.5.6.7.9.10.12.13.14.15.16. 17,20; specialty groups: ADD club, Kids Helping Kids, Creative Writina

NEW YORK

Techspress

Resource Ctr for Independent Livina 409 Columbia St Utica, NY 13502-0210 (315) 797-4642 (voice) (315) 797-5837 (TTY) (315) 797-4747 (fax) xprsny@aol.com 1,2,3,6,7,8,10,11,12,13,14,15, 18,19,20

NORTH CAROLINA

Carolina Computer Access Center

700 East Second St Charlotte, NC 28202-2826 (704) 342-3004 (voice/fax) 2 ccacnc@aol.com 1,2,4,5,6,8,9.10,12,15,16,19,20

NORTH DAKOTA

Pathfinder Services

of North Dakota 1600 2nd Ave SW Minot, ND 58701 (701) 852-9426 (voice) (701) 838-9324 (fax) pathfinder@aoi.com 1,5,7.9,11,12,13,14,15,16,18.20

Key to Services

- 1. Hands-on computer demonstrations
- 2. Guided exploration and problem-solving
- 3. Formal technologyneeds.assessments
- 4. Assistance in obtaining assistive technology funding
- 5. Software lending library
- 6. Loans of computers and hardware
- 7. Toy lending library
- 8. Loans of assistive devices
- 9. Videotage lending "brary
- 10. Constructing/adapting switches and devices
- 11. Technical assistance to IEP teams
- 12. Teacher training
- 13. Parent/family training
- 14. Augmentative communication training
- 15. Workshops
- 16, Early childhood/ preschool programs
- 17. Computer camps/ After-school programs
- 18. Transition training for young adults
- 19. Technical assistance to employers
- 20. Newsletter

OHO

Technology Resource Center

301 Valley St Dayton, OH 45404-1840 (513) 222-5222 (voice) (513) 222-2101 (fax) trcdoh@aol.com 1,2,4,5,6,7,8,9,10,11,12,13,14, 15, 16, 17, 18, 19, 20

RHODE ISLAND

TechACCESS Center

of Rhode Island 300 Richmond St Providence, RI 02903-4222 (401) 273-1990 (V/TTY) (401) 831-1131 (fax) accessri@aol.com 1.2,11,12,13,14,15,16 ,7.20

TENNESSEE

East Tennessee Special Technology Access Center 3525 Emory Rd NW

Powell, TN 37849 (615) 947-2191 (voice) (615) 947-2194 (fax) etstactn@aol.com 1,2,3,4,5,6,7,8,9,10,11,12,13,

15, 16, 17, 19, 20

1.



Emily Landau, 3, travels everywhere with her best friend, "Puffy," safely ensconced in the basket of her walker. Emily, who has Larsen syndrome and cervical kyphosis, is described by her mother as "bright, inquisitive and talkative." She lives in West Babylen, New York.

Technology Access Center of Middle Tennessee

2222 Metro Center Blvd, #126 Nashville, TN 37228 (615) 248-6733 (V/TT/) (615) 259-2536 (fax) stactn@aol.com 1,2,3,4,5,6,8,9,11,12,13,14,15,19,20

West Tennessee Special Technology Access Recource Center

60 Lynoak Cove
Jackson, TN 38305
(901) 668-3888 (voice)
(901) 668-1666 (fax)

4 startn@aol.com
1,2,3,4,5,6,7.8,10,12,13,14,15,
16,17,18,19,20

UTAH

Computer Center for Citizens with Disabilities

2056 S 1100 E
Salt Lake City, UT & 4106
(801) 485-9152 (V/TTY)
(801) 485-8675 (fax)

Carrow cccdut@aol.com
1,2,8,9,12,14,15,20

VIRGIN ISLANDS

Virgin Islands Resource Center for the Disabled

74-B & 75 Kronprindsen Gade Box 1825 St Thomas, USVI 00803 (809) 777-2253 (voice) (809) 774-5816 (fax) 1,3,4,7,9,11,12,13,14,15,16,17, 18,19,20

VIRGINIA

Tidewater Center for Technology Access

Special Education Annex
Celebration Station
3352 Virginia Beach Blvd, #112
Virginia Beach, VA 23452
(804) 431-4095 (V/TTY)
(804) 431-4089 (fax)
23 tcta@aol.com
1,2,3,4,5,8,9,10,11,12,14,15.16.

WEST VIRGINIA

Eastern Panhandle Technology Access Center

110 Mordington, PO Box 987 Charles Town, WV 25414 (304) 725-6473 (V/TTY/fax) 24 eptac@aol.com 1,2,4,5,6,7,8,9,10,11,12,13.15, 16,17,18,19,20

Project GLUE

South Charleston Public Library 312 4th Ave S Charleston, WV 25303 (304) 342-6501 (V/TTY) 29 glueata@aol.com 1,2,12,13,15

CANADA

Alliance Centre for Technology

360 George St N #202
Peterborough, Ontario K9J7E7
(705) 741-4214 (V/TTY)
(705) 741-4581 (fax)

☑ alliance@trentu.ca
1,2,3,4,10,12;13,14,15,19.20

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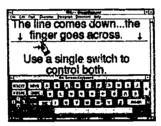
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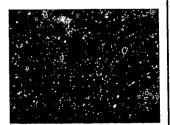
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PRODUCT NEWS



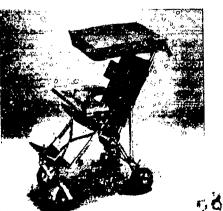
Lightweight Portability Solves Transport Problem

Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily lift and store the buggies in a car trunk. Great for indoor or outdoor use.



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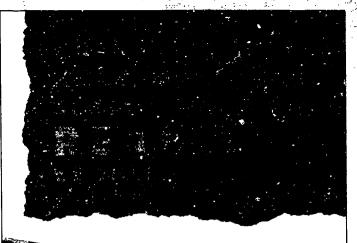
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SENATOR TOM HARKIN



TONY COELHO, Chairman President's Committee on Employment of People with Disabilities



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DR. JENNIFER L. HOWSE



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e JAMES E. WILLIAMS. JR. President and CEO. National Euster Seal Society.



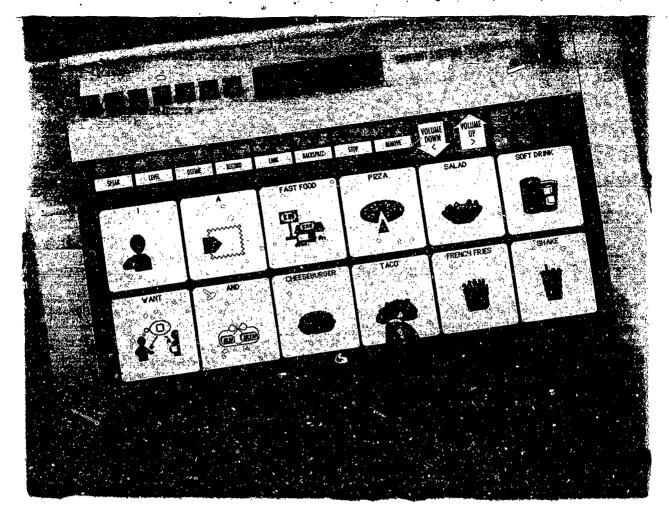
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TECHNOLOGY INC.



STATE ASSISTIVE TECHNOLOGY PROGRAMS

The following state assistive technology programs are funded by the National Institute on Disability and Rehabilitation Research (NIDRR) under the Technology-Related Assistance For Individuals With Disabilities Act of 1988 (and Amendments of 1994). For more information, contact the RESNA Technical Assistance Project, 1700 North Moore St., Ste. 1540, Arlington, VA 22209-1903; (703) 524-6686, (voice); (703) 524-6630, (TTY).

A description of services provided by individual programs follows each listing. Numbers correspond to items listed in the Key to Services.

This symbol () indicates an Internet e-mail address.

ALABAMA

Statewide Technology Access and Response System for Alabamians with Disabilities

2125 E South Blvd PO Box 20752 Montgomery, AL 36120-0752 (205) 288-0240 (voice) (205) 281-2276 (TTY) (205) 288-7171 (fax) 1.2.4.5

ALASKA

Assistive Technologies of Alaska

701 E Tudor Rd, Ste 280 Anchorage, AK 99503-7445 (907) 563-0318 (V/TTY) (907) 563-0146 (fax) 1,2,3,4,5,6,8

AMERICAN SAMOA

Assistive Technology Project

Division of Vocational Rehabilitation Department of Human Resources Pago Pago, American Samoa 96799 (684) 633-5010 (voice) (684) 633-7874 (TTY) (684) 633-2393 (fax) 1.2.3.4.5.7.8.9

ARIZONA

Arizona Technology Access Program

2600 N Wyatt Dr. 2nd Fl Tucson, AZ 85712 (800) 477-9921 (voice: AZ only) (602) 324-3170 (voice) (602) 324-3177 (TTY) (602) 324-3176 (fax)

demetras@ccit.arizona.edu 1,2,3,4,5,6,8 (some services still under development)

ARKANSAS

Increasing Capabilities Access Network

2201 Brookwood, Ste 117 Little Rock, AR 72202 (800) 828-2799 (V/TTY; AR only) (501) 666-8868 (V/TTY) (501) 666-5319 (fax) 1,2,3,4,5,6,9

CALIFORNIA

California Assistive Technology System

CA Department of Rehabilitation 830 K St Sacramento, CA 95814 (916) 324-3062 (V/TTY) (916) 324-7386 (TTY) (916) 323-0914 (fax) 1.7: newsletter

COLORADO

The Colorado Assistive Technology Program

Rocky Mountain Resource and Training Institute 6355 Ward Rd, Ste 310 Arvada, CO 80004 (800) 255-3477 (V/TTY; CO only) (303) 420-2942 (V/TTY) (303) 420-8675 (fax) 1.2,3,4; technology-related advocacy

CONHECTICUT

Assistive Technology Project

Bureau of Rehabilitation Services 10 Griffin Rd N Windsor, CT 06095 (203) 298-2042 (voice) (203) 298-2018 (TTY) (203) 298-9590 (fax) 1,2,5,7

DELAWARE

Delaware Assistive Technology Initiative

University of Delaware Al duPont Institute 1600 Rockland Rd, Rm 154 Wilmington, DE 19899 (302) 651-6790 (voice) (302) 651-6794 (TTY) (302) 651-6793 (fax) 1,2,3,4,5,6,8

DISTRICT OF COLUMBIA

Partnership for Assistive Technology

National Rehabilitation Hospital 801 Pennsylvania Ave SE, Ste 210 Washington, DC 20003 (202) 639-9510 (voice) (202) 639-0477 (TTY) (202) 639-0478 (fax) 1,2,3,4,5,6,7,8

FLORIDA

Alliance for Assistive Service and Technology

2002 Old St Augustine Rd, Bldg A Tallahassee, FL 32399-0696 (904) 487-3278 (V/TTY) (904) 488-8062 (fax) 1.3

GEORGIA

Tools for Life

Division of Rehabilitation Services 2 Peachtree St NW, Ste 23-411 Atlanta, GA 30303 (800) 497-8665 (voice: GA only) (404) 657-3084 (V/TTY) (404) 657-3085 (TTY) (404) 657-3086 (fax) 1.2.3,4,6,8,9; annual conference, seven regional technology demonstration centers

GUAM

System for Assistive Technology

University Affiliated Frogram-**Developmental Disabilities** University of Guam **UOG Station** Mangilao, Guam 96923 (671) 734-9309 (voice) (671) 734-5709 (fax) sspencer@uog.edu 1,2,3,5

Key to Services

- 1 Information and referral services
- 2 Assistance in obtaining funding for assistive devices and services
- 3 Equipment demonstration center
- 4 Equipment loan program
- 5 Training in assistive technology use
- 6 Equipment exchange and recycling program
- 7 Financial loan program for the purchase of assistive technology and services
- 8 Peer support groups
- 9 Mobile van outreach service

HAWAII

Assistive Technology Training and Services

677 Ala Moana Blvd, Ste 403 Honolulu, HI 96813 (808) 532-7110 (V/TTY) (808) 532-7120 (fax) 1,2,4,5,7,9; video loans

IDAHO

Assistive Technology Project

129 W Third St Moscow, ID 83843 (800) 432-8324 (V/TTY; ID only) (208) 885-3559 (voice) (202) 885-3628 (fax) tifield@uidaho.edu 1,2,3,5,6,7,8; regional resource centers

ILLINOIS

Assistive Technology Project

110 lles Park Pl Springfield, IL 62718 (800) 852-5110 (V/TTY; IL only) (217) 522-7985 (V/TiY) (212) 522-8067 (fax) ilat@gteens.com

1,2,3,4,5,9



STATE ASSISTIVE TECHNOLOGY PROGRAMS

ATTAIN: Accessing Technology Through Awareness in Indiana Project

PO Box 7083 402 W Washington St, Rm W453 Indianapolis, IN 46207-7083 (800) 545-7763 (V/TTY) (317) 232-1410 (V/TTY) (317) 232-6478 (fax) 1,2,5,6,8,9

lowa Program for Assistive Technology

lowa University Affiliated Program University Hospital School Iowa City, IA 52242 (800) 331-3027 (V/TTY) (319) 353-6386 (V/TTY) (319) 356-8284 (fax) 1,2,5,6,8

Assistive Technology for Kansans Project

2601 Gabriel Parsons, KS 67357 (316) 421-8367 (voice) (316) 421-0954 (TTY) (316) 421-0954 (fax) 1,2,3,4,5,6,8

Assistive Technology Services Network

427 Versailles Rd Frankfort, KY 40601 (800) 327-5287 (voice) (502) 573-4665 (V/TTY) (502) 573-3976 (fax) 1,2,3,4,5,6: four regional centers

Louisiana Assistive Technology Access Network

PO Box 3455, Bin #14
Baton Rouge, LA 70821-3455
(800) 922-3425 (voice)
(800) 256-1633 (TTY)
(504) 342-8821 (voice)
(504) 342-1970 (fax)
1,2,3.5; rural/low-income/minority outreach

Consumer Information and Technology Training Exchange

Maine CITE Coordinating Ctr Education Network of Maine 46 University Dr Augusta, ME 04330 (207) 621-3195 (V/TTY) (207) 621-3193 (fax) 5; Coordinates sub-grant activities which provide direct services

Technology Assistance Program

Governor's Office for Individuals with Disabilities
300 W Lexington St, Box 10
Baltimore, MD 21201
(800) 832-4827 (V/TTY)
(410) 333-4975 (V/TTY)
(410) 333-6674 (fax)
1,2,3,4.5,6,7; theatre audio description, rural/minority out-reach

Massachusetts Assistive Technology Partnership Center

Children's Hospital
1295 Boylston St, Ste 310
Boston, MA 02215
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(617) 735-6345 (fax)
(800) 950-6287 (2400-baud BBS; MA only)
(617) 267-5027 (2400-baud BBS)
1,2,5; newsletter, fact sheets, curricular and training materials, needs assessments

Tech 2000

PO Box 30010 Lansing, MI 48909-7510 (517) 335-6874 (voice) (517) 373-4035 (TTY) (517) 373-0565 (fax) 1,8

Star Program

300 Centennial Bldg 658 Cedar St St Paul, MN 55155 (800) 657-3862 (voice) (800) 657-3896 (TTY) (612) 282-6671 (fax) 1,2,5,6,8,9; regional resource centers, graduate-student internships

Project Start

PO Box 1000 Jackson, MS 39205-1000 (800) 852-8328 (V/TTY; MS only) (601) 987-4872 (V/TTY) (601) 364-2349 (fax) 1,2.3.4.5

Assistive Technology Project

4731 S Cochise, Ste 114 Independence, MO 64055-6975 (816) 373-5193 (voice) (816) 373-9315 (TTY) (816) 373-9314 (tax) 1.2,3,5,6,8: individual advocacy training

Montech

University of Montana, MUARID, MonTECH 634 Eddy Ave Missoula, MT 59812 (800) 732-0323 (V/TTY) (406) 243-4730 (fax) 1,2,3,4,6,7,8; six regional outreach centers --

Assistive Technology Project

301 Centennial Mall S PO Box 94987 Lincoln, NE 68509-4987 (402) 471-3647 (V/TTY) (402) 471-0117 (fax)

mschultz@nde4.nde.state.ne.us 1,2,3,4,5,6,8

Assistive Technology Preject

Rehabilitation Division
Office of Community Based
Services
711 S Stewart St
Carson City, NV 89710
(702) 687-4452 (voice)
(702) 687-3388 (TTY)
(702) 687-3292 (fax)
Referrals to local resources

Assistive Technology Partnership Project

University of New Hampshire Institute on Disability/UAP Ten Ferry St, Unit #14 Concord, NH 03301-5019 (800) 427-3338 (V/TTY: NH only) (603) 224-0630 (V/TTY) (603) 226-0389 (fax) 1.2,3,4.5,6,7

Technology Assistive Resource Program

135 E State St, CN 398 Trenton, NJ 08625 (800) 342-5832 (voice; NJ only) (800) 382-7765 (TTY; NJ only) (609) 292-8347 (voice) (609) 292-4616 (fax) 1,2.3.6.8

Key to Services

- 1 Information and referral services
- 2 Assistance in obtaining funding for assistive devices and services
- 3 Equipment demonstration center
- 4 Equipment loan program
- 5 Training in assistive technology use
- 6 Equipment exchange and recycling program
- 7 Financial loan program for the purchase of assistive technology and services
- 8 Peer support groups
- 9 Mobile van outreach service

Technology Assistance Program

435 St Michael's Dr, Bldg D Santa Fe, NM 87503 (800) 866-2253 (V/TTY) (505) 827-3746 (fax)

stdvnmtap@technet.nm.org 1.2,3,4,5,6,7.8,9

State TRAID Project

Office of Advocates for Persons with Disabilities
One Empire State Plaza, Ste 1001
Albany, NY 12223-1150
(800) 522-4369 (V/TTY; NY only)
(518) 474-2825 (voice)
(518) 473-4231 (TTY)
(518) 473-6005 (fax)
1,2,3,4,5,6

Assistive Technology Project

Dept of Human Resources
Division of Vocational
Rehabilitation Services
1110 Navaho Dr, Ste 101
Roleigh, NC 27609
(800) 852-0042 (voice)
(919) 850-2787 (V/TTY)
(919) 850-2792 (fax)
atp@med.unc.edu
1,2,3,5,6,8

STATE ASSISTIVE TECHNOLOGY PROGRAMS

Interagency Program for Assistive Technology

PO Box 743 Cavalier, ND 58220 (701) 265-4807 (V/TTY) (702) 265-3150 (fax)

leej@warp6.cs.misu.nodak.edu 1,2,4,5,9

Assistive Technology Project

Governor's Developmental Disabilities Council PO Box 2565 Saipan, MP 96950 (670) 322-3014 (V/TTY) (670) 322-4168 (fax) 1.2.6

TRAIN: Technology-Related **Assistance Information** Network

Ohio SuperComputer Ctr 1224 Kinnear Rd Columbus, OH 43212 (800) 784-3425 (V/TTY; OH only) (614) 292-2426 (V/TTY) (614) 292-5866 (fax) 1,2,3,5,6,7,8; electronic network on assistive technology with school districts

Oklahomal ABLE Tech

Dept of Rehabilitation Services PO Box 36659 Oklahoma City, OK 73136 (800) 316-4119 (V/TTY; OK only) (405) 427-3312 (V/TTY) (405) 427-3027 (fax) willing@ix.netcom.com

1,2,3,4.5,8

Technology Access for Life Needs Project

Chemeketa Community College PO Box 14007 Salem, OR 97309-7070 (800) 677-7512 (V/TTY; OR only) (503) 399-4950 (V/TTY) (502) 392-6978 (fax) susan.mcnaught

@p10.f99.n105.z1.fidonet

1,2.3,4.5.6

Pennsylvania's Initiative on **Assistive Technology**

Institute on Disabilities/UAP Temple University Ritter Hall Annex 433 (004-00) Philadelphia, PA 19122 (800) 204-7428 (V/TTY) (215) 204-1356 (V/TTY) (215) 204-6336 (fax)

piat@astro.ocis.temple.edu 1.2.3.4.5.6.8

Assistive Technology Project

University of Puerto Rico Medical Sciences Campus College of Health-Related Professions Dept of Communicological Disorders Box 365067 San Juan, PR 00936-5067 (800) 496-6035 (From US mainland) (800) 981-6033 (PR only) (809) 764-6035 (voice) (809) 754-8034 (TTY) (809) 759-3645 (fax) 1.2.3.5

Assistive Technology Access Project Dept of Human Services, Div of

Community Services Office of Rehabilitation Services. Voc Rehab 40 Fountain St. 5th FI Providence, RI 02903-1898 (800) 752-8088, ext 2608 (RI only) (401) 421-7005 (voice) (401) 421-7016 (TTY) (401) 421-9259 (fax) 1.2.4

Assistive Technology Program

Vocational Rehabilitation Dept PO Box 15, 1410-C Boston Ave West Columbia, SC 29171-0015 (803) 822-5404 (V/TTY) (803) 822-4301 (fax) 1.2.3.4.5.6.7.8.9

Dakota Link

1925 Plaza Blvd Rapid City, SD 57702 (800) 645-0673 (V/TTY; SD only) (605) 344-1876 (V/TTY) (605) 394-5315 (fax) 1,2,3,4,5,6,9; six rural outreach centers

Technology Access Project

710 James Robertson Pkwy Gateway Plaza, 11th Fl Nashville, TN 37243-0675 (800) 732-5059 (voice; TN only) (615) 532-6530 (voice) (615) 532-6612 (TTY) (615) 532-6964 (fax) 1.2,3,4,5,9

Assistive Technology Partnership

University of Texas at Austin, **UAP of Texas** Department of Special Education. **EDB 306** £ ustin, TX 78712 4300) 828-7839 (voice) ,512) 471-7621 (voice) (512) 471-1844 (TTY) (512) 471-7549 (fax) 1,3,5,8,9

Utah Center for Assistive Technology

2056 South 1100 East Salt Lake City, UT 84106 (800) 333-8824 (V/TTY) (801) 485-9152 (V/TTY) (801) 797-2355 (fax) 1,2,3,4,5,6,7

Assistive Technology Project

103 S Main St. Weeks I Waterbury, VT 05671-2305 (802) 241-2620 (V/TTY) (802) 241-3052 (fax) 1,2,3,4,5,6,7

Assistive Technology System

8004 Franklin Farms Dr PO Box K-300 Richmond, VA 23288-0300 (800) 435-8490 (V/TTY: VA only) (804) 662-9998 (V/TTY) (804) 662-9478 (fax) Database BBS: (800) 238-7955 (VA only; 2400 baud) Equipment exchange BBS (804) 662-9477 (2400 baud) 1.3.6 (through BBS only)

Assistive Technology Alliance

DSHS/DVR PO Box 45340 Olympia, WA 98504-5340 (206) 438-8051 (V/TTY) (206) 438-8644 (TTY) (208) 438-8007 (fax) dhooks@wlu.com 1.2.3.6.9; legal advocacy, universal access to library systems

West Virginia Assistive **Technology System**

Airport Office and Research Park 955 Hartman Run Rd Morgantown, WV 26505 (800) 841-8436 (voice; WV only) (304) 293-4692 (V/TTY) (304) 293-7294 (fax) reb@wvnvm.wvnet.edu 1.2.3.4.5.8; newsletter, advocacy trainina

WisTech

Division of Vocational Rehabilitation PO Box 7852 1 W Wilson St, Rm 950 Madison, WI 53707-7852 (608) 266-1281 (voice) (608) 266-9599 (TTY) (608) 267-3657 (fax) tramof@aol.com 1,2,3,4,5,6,8; advocacy, legal assistance

WYNOT: Wyoming's New Options In Technology

Division of Vocational Rehabilitation 1100 Herschler Bldg Cheyenne, WY 82002 (800) 877-9975 (voice) (800) 877-9965 (TTY) (307) 777-7450 (voice) (307) 777-5939 (fax) 1,2,3,4,5; community resource team development and training



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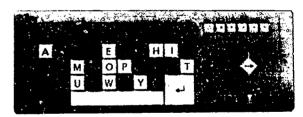
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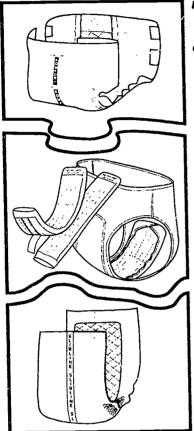
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DISABILITY-RELATED ELECTRONIC BULLETIN BOARDS

The disability-related bulletin board services (BBSs) listed below can provide a wealth of helpful information. Use of ail listed services is free, however, depending on where one lives, calling a BBS may incur long-distance telephone charges. A few bulletin boards charge fees for increased access or membership; when applicable, these fees are mentioned in the notes following each entry. Some boards chose to list voice numbers where the coordinator of the BBS, known as the system operator (sysop), can be reached for questions or

Unlike major commerical online services, these services do not provide special software. Instead, users must call the BBS using the communications software that came with their modems. Users must be sure to stay within the given baud rate per second for modems (bps)—this figure is listed after the BBS modern number (i.e., "up to 9,600 bps"). This is the only aspect of the communications software that the user must configure (set) differently for various BBSs; the other modem settings are the same for all listed services-8 data bits, no parity, 1 stop bit (8-N-1). (These are the default settings for most communications software—you don't need to understand what each means; you may not even need to change the configuration of your software from the default.)

Once connected to a BBS, users can post and read messages, upload (post) and download (receive) files and leave messages for the sysop. Certain boards are connected to larger networks, such as Internet, Fidonet or ADAnet, which allow files to be shared and messages to be posted among a large number of bulletin boards.

ALABAMA

ADAnet

(205) 254-6050, up to 2,400 bps All disability groups covered; many BBSs are linked to this system; many message areas, large file area for downloading; users get 30 free minutes daily; subscriptions (\$40/yr) allow increased usage and unlimited downloading.

ALASKA

Assistive Technology of Alaska BBS

(800) 770-1399 (AK only). ս, 2,400 bps (907) 277-1399 (out-of-state), up to 2,400 bps (800) 636-0138 (voice) (907) 563-0140 (voice) Forums on specific disabilities, education, assistive technology, legislation; files for downloading.

ARIZONA

Tucson Prologue

(602) 322-8014,

up to 14,400 bps General disabilities, some emphasis on blindness; Internet e-mail, Fidonet: message areas, files for downloading; local issues; most users are adults with disabilities.

CALIFORNIA

BavTaik

(415) 864-6430; up to 9,600 bps Emphasis on computer-access issues for persons with disabilities: message/file areas concerning Americans with Disabilities Act, info for parents on local issues.

Blink Connection

(510) 276-4121, up to 2,400 bps Emphasis on visual impairments; message areas; some Fidonet access; BBS can be used by persons with visual impairments.

Disabled Children's **Computer Group**

(510) 841-5621, up to 9,600 bps (510) 841-3224 (voice) Emphasis on children with disabilities, conferences for adults, families-parents are welcome; Fidonet: info on local resources, files for downloading.

KIRO Education BBS

(805) 324-2955,

up to 14,400 bps Emphasis on blindness, education; BBS use is free/\$5.00 monthly fee for Internet access: Fidonet, Internet e-mail/newsgroups; National Federation of the Blind forums, publications onlinehelpful materials for parents.

LINCS-BBS

(408) 294-6933.

up to 14,400 bps (408) 277-0764

up to 14,400 bps (408) 288-5010 (voice) General disabilities, emphasis on children; Parents Helping Parents (PHP) members (\$25 annual fee) receive Internet e-mail: message areas, "Parents Search" area, resource directories, info on rare conditions, local legislative updates; files/games for downloading, PHP can provide technical assistance to resource centers interested in starting their own BBSs.

CONNECTICUT

Handicap News BBS

(203) 926-6168,

up to 14,400 bps (203) 926-6187 (voice) Wide range of disabilities-50-80 conference areas; Internet email/newsgroups, Fidonet; many conferences helpful to parents, local conference available, although most callers are nonlocal; nearly 1000 files for downloading; sysop is parent of child who has Down syndrome.

DISTRICT OF COLUMBIA

ACB On-Line (American **Council of the Blind)**

(202) 331-1058,

up to 14,400 bps (202) 467-5081 (voice) Emphasis on visual impairments; files on braille literacy, resource lists, archive of ACB literature.

ILLINOIS

COPH 2 BBS

(312) 436-0559, up to 2,400 bps General disabilities; message areas, files for downloading.

INDIANA

The Special Needs BBS

(219) 659-0112.

up to 14,400 bps General disabilities, some emphasis on hearing impairments; Internet e-mail, Fidonet, Health Care Net access; message areas for parents, files/programs for downloading; sysop is parent of child who is deaf.

MAINE

Maine Meeting Place BBS

(800) 339-3845 (ME only), up to 28,800 bps

(207) 324-5310 (Outside ME), up to 28,800 bos

(207) 324-2337 (voice) Wide range of disabilities, related issues; BBS designed to accommodate computer novices-many parents are users; Internet email/newsgroups; local issues; outreach to groups/individuals who need low-cost computer equipment.

MARYLAND

ABLE INFORM

(301) 589-3563, up to 9600 bps Emphasis on assistive technology and rehabilitation/disability literature; Searchable databases. resource guides, fact sheets.

Braille Inn BBS

(410) 893-8944, up to 9,600 bps General disability issues; files in and about braille; Fidonet.



DISABILITY-RELATED ELECTRONIC BULLETIN BOARDS

Deaf New World BBS

(301) 587-2277,

up to 14,400 bps (301) 588-0965 (TTY) (301) 588-0548 (voice)

(301) 588-5261 (fax)

Emphasis on deafness; TTY-compatible; 30 minutes free access daily—subscribers (varying rates) receive more time and Internet email; Fidonet; online shopping areas for deaf-related products; files for downloading.

HEX BBS

(301) 593-7357, up to 9,600 bps General disabilities; TTY-compatible; Fidonet; message areas, files for downloading.

NFB Net (National Federation of the Blind)

(410) 752-5011,

up to 14,400 bps (410) 659-9314 (voice) Emphasis on visual impairments; NFB literature/publications online, conferences for parents to discuss issues with adults who are blind:

Fidonet, ADAnet; electronic books/text files for downloading.

MASSACHUSETTS

Disabled Individuals Movement for Equality Network (DIMENET)

(508) 880-5412,

up to 14,400 bps (513) 237-8360 (voice) DIMENET is a coalition of Independent Living Center (ILC) BBSs working to obtain resources for online computing for all ILCs. The BBSs are based in Taunton, MA: Dayton, OH and Tulsa, OK; general disabilities, ILC related issues; Internet e-mail/news-groups; Fidonet; files for downloading.

Mass. Commission for the Blind BBS

(617) 451-5327,

up to 14,400 bps (800) 392-6450 (voice; MA only) (617) 727-5550 (voice) Emphasis on visual impairments:

message areas, conferences, employment info, conference info for parents; files for downloading.

VIBUG BBS (Visually Impaired/Blind Users Group) (617) 767-2909,

up to 14,400 bps Emphasis on visual impairments; conferences for parents; Fidonet; files for downloading.

MICHIGAN

Blind Ambition BBS

(810) 651-4009,

up to 2,400 bps Sponsored by Leader Dogs for the Blind, Rochester Hills, MI; emphasis on visual impairments; message areas, files/programs for bling users for downloading.

MINNESOTA

Blind Services BBS

(612) 642-0483, up to 2,400 bps Sponsored by Minnesota Services for the Blind; some emphasis on visual impairments; Fidonet; message areas, files for downloading.

Disability Resources Affiliates & Groups Network (DRAGNET) (612) 753-1943.

up to 14,400 bps (612) 827-2294 (V/TTY) Wide range of disability issues; free access, user guide available for suggested \$5 donation; Inlernet, Fidonet, ADAnet; conferences for parents, will put other groups' newsletters online for free; many non-local callers; files for downloading.

MISSOURI

SSMART BBS

(314) 781-6397, up to 9,600 bps (314) 768-5312 (voice) Forums on brain injuries, stroke, spinal cord injuries, other disabilities; forum for parents; local issues; files for downloading.

NEW JERSEY

Disabilities Electronic Network (DEN)

(201) 342-3273, up to 14,400 bps (201) 342-6984 (voice) Wide range of disabilities; Fidonet, ADAnet; message areas on specific disabilities, message area for parents, files for downloading.

NEW YORK

Access BBS

(518) 885-4192,

up to 16,800 bps General disabilities; Internet email, Fidonet, ADAnet. AEGIS (AIDS Education General Information Service); files specific to children with disabilities, resource info, local conferences, files for downloading.



Maxwell Monde, 18 months, enjoys sitting in the jacuzzi with his dad, David. Max developed a grade IV intraventricular hemorrhage and hydrocephalus before birth. As a result, he has mild cerebral palsy and a visual impairment. Max, who loves any activity involving water, enjoys bathtime almost as much as those father-son soaks in the jacuzzi.

OHIO

Disabled Individuals Movement for Equality Network (DIMENET) (513) 439-0557,

up to 14,400 bps (513) 237-8360 (voice) See DIMENET/Massachusetts.

OKLAHOMA

Disabled Individuals Movement for Equality Network (DIMENET) (918) 582-3622,

up to 14,400 bps (513) 237-8360 (voice)

See DIMENET/Massachusetts.

OREGON

The DisAbility BBS

(503) 777-6561,

up to 14,400 bps General disabilities; 42 conference/message areas—LD, ADD areas recommended for parents; Fidonet, ADAnet; tiles for downloading.

PENNSYLVANIA

Sounding Board BBS

(412) 621-4604.

up to 14,400 bps Emphasis on deaf-blind, visual/hearing impairments; conferences for specific disabilities; Fidonet: files for downloading.

TEXAS

CCAD Online

(214) 647-5739, up to 2,400 bps Emphasis on assistive technology, education; BBS mostly accessible for persons using assistive technology; message areas, files for downloading.

Microtalk BBS

(903) 832-3722, up to 2,400 bps General disabilities, local issues, message areas, files for downloading.

VIRGINIA

Handiline BBS

(703) 536-4182, up to 9,600 bps General disabilities, local issues; message areas.

WEST VIRGINIA

Project Enable

(304) 759-0727, up to 9,600 bps General disabilities; Fidonet, ADAnet; many message areas.

CANADA

ONTARIO

Abilities OnLine

(416) 650-5411,

up to 14,400 bps (416) 650-6207 (voice) Wide range of disabilities; message areas mainly for kids, some for parents; ADAnet, Internet email/newsgroups; resources for parents; files for downloading.

Disability Access

(613) 837-5473, up to 9,600 bps General disabilities; local issues; resource information.

BRITISH COLUMBIA

TASH On-Line Disability Resources

(604) 856-3661, up to 14,400 bps (604) 856-4778 (voice) Wide range of disabilities, health/education issues; Fidonet, Health care net, Internet; local resources; software for preschoolers/files for downloading; will provide assistance to anyone who wants to start a BBS.

ERIC

Life Planning Should Be A Team Effort

Providing for the future needs of a family member with a disability can be a complicated matter. Families often need the help of those with specific knowledge and experience to be certain they are making the best choices for their loved one. The Life Planning Team shown here includes the person with a disability, family

members, attorney and EPPD Representative.

Estate Planning for Persons with Disabilities (EPPD) provides essential information and guidelines to hundreds of families every month. Our national network of skilled and experienced local attorneys and estate planners can assist families with a son or daughter who has a disability to develop comprehensive life plans including wills, special needs trusts, guardianships, advocacy, balancing private government benefits. **EPPD** representatives provide FREE initial interve ws to determine your needs and FREE group seminars for parents. We have an office near you. EPPD is not a guardianship or master trust plan, but assists parents in locating the services necessary to provide a secure future for their loved one.

Read the following comments from just a few of our satisfied clients:

"I appreciate the good service I received in planning for my disabled daughter's future. I liked the way you handled everything, going through the many details with me thoroughly." Marie G. Savard, Glendale, CA

"Our EPPD Planner did a great job in helping us to finalize all the essential areas of planning for our daughter's future. She stepped in and helped fill in the gaps that we had not considered. We are confident and feel good that her future will be secure."

Jim and Michele Lee, Fort Collins, CO

"We are enormously pleased with all the work our EPPD planner did for us. We are very pleased with the results, as we know our daughter's future is secure."

Lois and Carl Westland, Ocean Shores, WA

"Your presentation was most informative on planning for the financial security of our disabled loved one. We greatly appreciate the knowledge you shared with us." Sandra J. Barcus, Scottsdale Head Injury Support Group, Scottsdale, AZ

"The EPPD seminar was great, More people should take advantage of this opportunity and learn how to prepare for the future." Pam Weiner, Haverhill, MA

"Our EFPD planner has been an invaluable resource to our community. His knowledge. experience and commitment has been a blessing for many families."

Evelyn G. Johnson, Houston, TX

"Your presentation on estate planning was well received and we received a lot of positive feedback. Information on this topic can sometimes be overwhelming, but you present the material in a clear, concise manner." Deborah Wilson, Missouri Head Injury Association, Jefferson City, MO

"The work our estate planner did helped to put our minds at ease. It was very thorough."

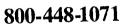
Karen Cockehan, New Orleans, LA

"Just the kind of planning I had been looking for. The seminar helped me to understand just what we needed to do in order to provide for our son." Connie Griffin, Athens, AL

"We found the process EPPD used worked well for us. They brought together all the planning services necessary to allow us to reduce our concerns." Mr. and Mrs. S. Butler, Albuquerque, NM

Call today to receive a FREE brochure and the location of your local EPPD representative.

EPPD would be pleased to do an educational seminar for your group.



Richard W. Fee, **Executive Director**

National Office 1200 Corporate Drive Suite 330 Birmingham, Alabama 35242

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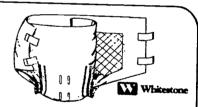
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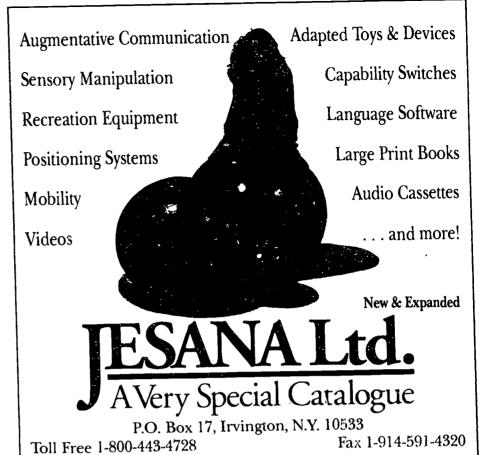
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FEDERAL & FEDERALLY-FUNDED INFORMATION RESOURCES

The federal government supports many clearinghouses, information centers and institutes that focus on specific topics. In addition to publishing and distributing extensive free material on disability-related subjects, many of the clearinghouses, centers and institutes also provide referrals to local resources.

For more information on federal and federally-funded information resources, contact:

- NICHCY (National Information Center for Children and Youth with Disabilities), 1875 Connecticut Ave NW, Washington, DC 20009, (800) 695-0285 (V/TTY), (202) 884-8741 (fax).
- NARIC (National Rehabilitation Information Center), 8455
 Colesville Rd, Ste 935, Silver Spring, MD 20910, (800) 346-2742, (301) 588-9284 (V/TTY), (301) 587-1967 (fax).
- NHIC (National Health Information Center), P.O. Box 1133, Washington, DC 20013-1133, (800) 336-4797 (voice), (301) 984-4256 (fax).

GENERAL

Clearinghouse on Disability Information

Office of Special Education and Rehabilitation Services US Dept of Education 330 C St SW Switzer Bldg, Rm 3132 Washington, DC 20202-2524 (202) 205-8241 (V/TTY) (202) 205-9252 (fax)

National Center for Education in Maternal and Child Health

2000 15th St N, Ste 701 Arlington, VA 22201-2617 (703) 524-7802 (voice) (703) 524-9335 (fax)

National Health Information Center

PO Box 1133 Washington, DC 20013-1133 (800) 336-4797 (voice) (301) 984-4256 (fax)

National Information Center for Children and Youth with Disabilities (NICHCY)

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National institute of Child Health and Human Development

PO Box 29111 Washington, DC 20040 (301) 496-5133 (voice) (301) 496-7101 (fax)

National Maternal and Child Health Clearinghouse

8201 Greensboro Dr, Ste 600 McLean, VA 22102 (703) 821-8955, ext 254, 265 or 317 (voice) (703) 821-2098 (fax)

National Rehabilitation Information Center (NARIC)

8455 Colesville Rd, Ste 935 Silver Spring, MD 20910 (800) 346-2742 (V/TTY) (301) 588-9284 (V/TTY) (301) 587-1967 (fax)

Office of Minority Health Resource Center

PO Box 37337 Washington, DC 20013 (800) 444-6472 (voice) (301) 565-5112 (fax)

AIDS

Centers for Disease Control and Prevention National AIDS Clearinghouse

PO Box 6003 Rockville, MD 20849-6003 (800) 458-5231 (voice) (800) 342-AIDS (English hotline) (800) 344-SIDA (Spanish hotline) (800) 243-7012 (TTY) (301) 738-6616 (fax) (301) 217-0023 (International line)

National Pediatric HIV Resource Center

15 S 9th St Newark, NJ 07107 (800) 362-0071 (voice) (201) 268-8251 (voice) (201) 485-2752 (fax)

ALLERGY & INFECTIOUS DISEASES

National Institute of Allergy and Infectious Diseases

Office of Communication Bldg 31, Rm 7A50 9000 Rockville Pike Bethesda, MD 20892 (301) 496-5717 (voice) (301) 402-0120 (fax)

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CANCER

Cancer Information Service

National Cancer Institute Bldg 31, Rm 10A16 Bethesda, MD 20892 (800) 422-6231 (voice)

DEAF-BLIND

National information Clearinghouse on Children Who Are Deaf-Blind

345 N Monmouth Ave Monmouth, OR 97361 (800) 438-9376 (voice) (800) 854-7013 (TTY) (503) 838-8150 (fax)

DIABETES

National Diabetes Information Clearinghouse

1 Information Wy Bethesda, MD 20892-3560 (301) 654-3327 (voice) (301) 907-8906 (fax)

DIGESTIVE DISEASES

National Digestive Diseases Information Clearinghouse

2 Information Wy Bethesda, MD 20892-3570 (301) 654-3810 (voice) (301) 907-8906 (fax)

EDUCATION

ERIC Clearinghouse on Disabilities and Gifted Education

Council for Exceptional Children 1920 Association Dr Reston, VA 22091-1589 (800) 328-0272 (voice) (703) 264-9474 (voice) (703) 620-3660 (TTY)

National Clearinghouse on Postsecondary Education for Individuals with Disabilities

HEATH Resource Center
1 Dupont Cir NW, Ste 800
Washington, DC 20036-1193
(800) 544-3284 (V/TTY)
(202) 939-9320 (V/TTY)
(202) 833-47560 (fax)

HEARING IMPAIRMENTS

National Information Center on Deafness

Gallaudet University 800 Florida Ave NE Washington, DC 20002-3695 (202) 651-5051 (voice) (202) 651-5052 (TTY) (202) 651-5054 (fax)

National Institute on Deafness and Other Communication Disorders Information Clearinghouse

1 Communication Ave Bethesda, MD 20892-3456 (800) 241-1044 (voice) (800) 241-1055 (TTY)

HEART, LUNG & BLOOD DISORDERS

National Heart, Lung, and Blood Institute information Center

PO Box 30105 Bethesda, MD 20824-0105 (301) 251-1222 (voice) (301) 251-1223 (fax)

HOUSING

Housing and Urban Development User PO Box 6091

Rockville, MD 20850 (800) 245-2691 (voice) (800) 887-8339 (TTY) (301) 251-5747 (fax)



KIDNEY & UROLOGIC DISEASES

National Kidney and Urologic **Diseases Information** Clearinghouse

3 Information Wy Bethesda, MD 20892-3580 (301) 654-4415 (voice) (301) 907-8906 (fax)

MENTAL HEALTH

National Clearinghouse on Family Support and Children's Mental Health

Portland State University . PO Box 751 Portland, OR 97207-0751 (800) 628-1696 (voice) (503) 725-4040 (voice) (503) 725-4165 (TTY) (503) 725-4180 (fax)

National Institute of Mental Health

Information Resources and Inquiries Branch 5600 Fishers Ln, Rm 7C-02 Rockville, MD 20857 (301) 443-4513 (voice) (301) 4:3-8431 (TTY)

MUSCULOSKELETAL & SKIN DISEASES

National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse 1 AMS Cir

Bethesda, MD 20892-3675 (301) 495-4484 (voice) (301) 587-4352 (fax)

NEUROLOGICAL DISORDERS

National Institute of Neurologica! Disorders & Stroke

PO Box 5801 Bethesda, MD 20824 (800) 352-9424 (voice) (301) 496-5751 (voice) (301) 402-2186 (fax)

ORAL HEALTH

National Oral Health Information Clearinghouse

1 NOHIC Wy Bethesda, MD 20892 (301) 402-7364 (voice) (301) 907-8830 (fax)

PRIMARY CARE

National Clearinghouse for Primary Care Information

8201 Greensboro Dr. Ste 600 McLean, VA 22102 (703) 821-8955, ext 248 (voice) (703) 821-2098 (fax)

SUDDER INFANT DEATH SYNDROME

National Sudden Infant Death **Syndrome Resource Center**

8201 Greensboro Dr. Ste 600 McLean, VA 22102-3810 (703) 821-8935 (voice) (703) 821-2098 (fax)

VISUAL IMPAIRMENTS

National Eye Institute Bldg 31, Rm 6A32

31 Center Dr. MSC 2510 Bethesda, MD 20892-2510 (301) 496-5248 (voice) (301) 402 1065 (fax)

OTHER FEDERAL RESOURCES

These federal resources can provide information on programs, services and related laws and regulations.

Administration on Developmentai Disabilities

US Dept of Health and **Human Services** HHH Bldg, Rm 329D 200 Independence Ave SW Washington, DC 20201 (202) 690-6590 (voice) (202) 690-6415 (TTY) (202) 690-6904 (fax) Develops and administers programs protecting rights and promoting independence, productivity and inclusion: funds state grants. the Protection and Advocacy programs, University Affiliated Programs and national projects.

Division of Birth Defects and Developmental Disabilities

National Ctr for Environmental Health Centers for Disease Control and Prevention 4770 Buford Hwy NE Mailstop F-45 Atlanta, GA 30341-3724 (404) 488-7150 (voice) (404) 488-7156 (fax) Provides assistance to community organizations to implement prevention programs.

Indian Health Service

Parklawn Bldg, Rm 2014 5600 Fishers Ln Rockville, MD 20857 (301) 443-3593 (voice) (301) 443-0507 (fax) Counseling and referrals to American Indian and Alaska Native families with children with disabilities.

National Library Service for the Blind and Physically Handicapped

Library of Congress 1291 Taylor St NW Washington, DC 20542 (202) 707-5100 (voice) (202) 707-0744 (TTY) (202) 707-0712 (fax) Provides Braille and recorded books and magazines on free loan to anyone who cannot read standard print because of visual or physical disabilities.

Office of Fair Housing and **Equal Opportunity** Dept of Housing and Urban

Development Office of Fair Housing and Equal Opportunity 820 1st St NE, Ste 450 Washington, DC 20002 (202) 275-0848 (voice) (202) 275-0772 (TTY) (202) 275-0779 (fax) Provides information and handles complaints about discrimination in housing.

Office of Special **Education** and Rehabilitative Services (OSERS)

US Dept of Education Switzer Bldg 330 C St SW Washington, DC 20202 (202) 205-8723 (voice) (202) 205-8241 (TTY) (202) 205-9252 (fax) Supports educational programs for children with special needs, rehabilitation and research.

President's Committee on **Employment of People** with Disabilities

1331 F St NW, 3rd FI Washington, DC 20004 (202) 376-6200 (voice) (202) 376-6205 (TTY) (202) 376-6219 (fax) Publishes and distributes free material on employment of people with disabilities. independent living, the Rehabilitation Act and job accommodation and placement.

President's Committee on Mental Retardation

Wilbur J Cohen Bldg, Rm 5325 330 Independence Ave SW Washington, DC 20201 (202) 619-0634 (voice) (202) 205-9519 (fax) Advises the administration on providing services for people with mental retardation and on ways to prevent this disability. Publishes annual reports, bibliographies, conference reports and information on related topics.

Senate Subcommittee on Disability Policy

113 Hart Senate Office Bldg Washington, DC 20510 (202) 224-6265 (voice) (202) 224-3457 (TTY) (202) 228-2923 (fax) Has legislative jurisdiction over the Americans with Disabilities Act (ADA), Individuals with Disabilities Education Act (IDEA). Rehabilitation Act. Developmental Disabilities Act and Techonology-Related Assistance for Individuals with Disabilities (TECH) Act.

Social Security Administration

6401 Security Blvd Baltimore, MD 21235 (800) 772-1213 (voice hotline) (800) 325-0778 (ITY hotline) (410) 965-7700 (voice) (410) 965-0695 (fax) Provides information about the Social Security and Supplemental Security Income (SSI) programs, disability benefits and entitlement to Medicare.

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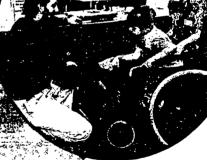
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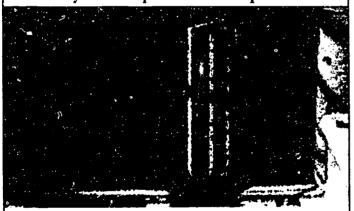
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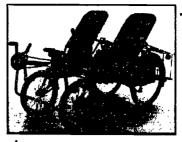
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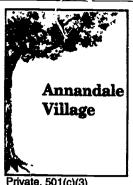


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Contact: Nathan Anderson Children's Care Hospital & School 2501 West 26th Street Sioux Falls, SD 57105-2498 (605) 336-1840 or (800) 584-9294



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6 + EXCEPTIONAL PARENT / JANUARY 1995



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estled in the serene beauty of western Massachusetts'
Berkshire Hills, Berkshire Meadows' carefully designed fifteen-acre campus offers a comprehensive, integrated year-round residential program for children and adolescents who are severely developmentally delayed and may be multiply disabled.

ike other children all over the world, residents of Berkshire Meadows attend "school" (our Learning Center) five days a week. Each follows his or her own curriculum, designed to respond to individual needs: physical development, cognitive development (based on Piaget), the use of basic living skills. Our program for young adults also includes Applied Academics: techniques such as the use of money, and basic computing. And as a corollary to the Total Communication techniques we apply throughout our program, all students participate in Augmentative Communication training, where individual methods of communication are developed.





The young people live in spacious one-story homes, each with its own lounge, visiting area, kitchen, dining room, laundry and specially-equipped bathrooms. Each youngster has a bright, attractive bedroom, and is encouraged to keep personal pictures and toys. Here, in an atmosphere of nurturing home life, each resident learns about self-care and daily living skills, and staff accommodate personal needs with respect and tenderness.

Each resident of Berkshire Meadows follows his or her own individualized physical therapy program. We take full advantage of all the tools and techniques that research and modern technology have provided to ease pain, relax muscles, develop strength and expand movement, including extensive hydrotherapy. Specialists in the fields of psychiatry and psychology work with the young people to promote emotional and mental well-being. Round-the-clock nursing coverage ensures that each child's physical needs are constantly and consistently monitored.

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ur intent is to help "our" young people to become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement and support. We believe that with thoughtful, cohesive integration of specialized education and physical care, and family and community support, each child has the opportunity to achieve his or her maximum potential, and, most importantly, to experience satisfaction and joy.

Berkshire Meadows
Gail Charpentier, Exec. Dir.
249 North Plain Road
Housatonic, MA 01236
(413) 528-2523



ess Report

May 94

Refore: Dec. 92

Outcomes: Posture, function, and mounty improved.

Comments: Bobby shows greater endurance and activity in the GS Cushion and Back.

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

Jay GS: Simple, cost-effective children's seating.

PROFESSIONAL ORGANIZATIONS

embership in many professional organizations is often limited to professionals working in specific fields. However, many organizations offer information and resources to non-members. If interested in specific organizations, please contact them for further details.

This directory was compiled with the help of NICHCY (National Information Center for Children and Youth with Disabilities), 1875 Connecticut Ave., NW, Washington, DC 20009, (800) 695-0285 (V/TTY), (202) 884-8441 (fax).

Academy of DENTISTRY for Persons with Disabilities

211 E Chicago Ave, Ste 948
Chicago, IL 60611
Assists dentists, dental hygienists, students and other dental care providers in acquiring and maintaining skills and knowledge to provide comprehensive dental care to people with disabilities.

American Academy of PEDIATRIC DENTISTRY

211 E Chicage Ave, Ste 700 Chicago, IL 60611 (312) 337-2169 (voice) (312) 337-6329 (fax) Represents 3,700 members in pediatric dentistry. Emphasizes three-part approach to caring for children: practice, teaching and research.

American Academy of PEDIATRICS

PO Box 927
Elk Grove Village, IL 60009
Represents 49,000 pediatricians.
Dedicated to the health, safety
and well-being of infants, children,
adolescents and young adults.
Committee on Children with
Disabilities studies the role of
pediatricians in the care of children with chronic illnesses and
disabilities.

American Alliance for HEALTH, PHYSICAL EDUCATION, RECREATION and DANCE

1900 Association Dr Reston. VA 22091 (703) 476-3400 (voice) (703) 476-9527 (fax) Concerned with improving physical education, sports, health and safety education, recreation and dance programs in schools and communities. Offers publications in planning, organizing and conducting programs for people with disabilities.

American ART THERAPY Association

1202 Allanson Rd Mundelein, IL 60060 (708) 949-6064 (voice) (708) 566-4580 (fax) Approves graduate-level training programs in art therapy and registers professional therapists.

American Association for VOCATIONAL INSTRUCTIONAL MATERIALS

220 Smithonia Rd Winterville, GA 30683 (800) 228-4689 (voice) (706) 742-7005 (fax) Publishes instructional books, videos and computer software on agriculture, home economics, and trade and industrial arts.

American Association of CHILDREN'S RESIDENTIAL CENTERS

1021 Prince St
Alexandria, VA 22314
(703) 838-7522 (voice)
(703) 684-5968 (fax)
Represents mental health facilities
that meet required standards in
therapeutic living, educational programs, group therapy and parent
or family therapy for children with
emotional problems. Provides
technical assistance for new residential treatment center programs.

American Association on MENTAL RETARDATION

444 N Capital St NW, Ste 846
Washington, DC 20001
(800) 424-3688 (voice)
(202) 387-1968 (voice)
(202) 387-2193 (fax)
Seeks to improve services to people who have mental retardation.
Offers professional v rkshops and consultations for tra. ing and technical assistance.

American Association of UNIVERSITY AFFILIATED PROGRAMS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

8630 Fenton St, Ste 410
Silver Spring, MD 20910
(301) 588-8252 (voice)
(301) 588-3319 (TTY)
(301) 588-2842 (fax)
Central office of the 54 university
affiliated programs (UAPs). UAPs
offer training of professionals and
para-professionals dealing with
people with developmental disabilities; screening, evaluation, treatment, planning and educational
programming; technical assistance to service agencies and dissemination of research findings.

American COUNSELING Association

5999 Stevenson Ave Alexandria, VA 22304 (703) 823-6862 (voice) (703) 823-0252 (fax) Provides professional counselors, counselor educators and related human development specialists with programs and services for personal and professional growth. Accredits counselor education programs.

American DANCE THERAPY Association

2000 Century Plaza, Ste 108
Columbia, MD 21044
(410) 997-4040 (voice)
(410) 997-4048 (fax)
Approves educational programs in dance/movement therapy and registers professional therapists.
Provides local professional contacts, free information on educational programs and guidelines for dance/movement therapy training and internships.

American HORTICULTURAL THERAPY Association

362A Christopher Ave Gaithersburg, MD 20879 (301) 948-3010 (voice) (301) 869-2397 (fax) Consults to institutions interested in establishing horticultural therapy programs. Registers professional therapists and sponsors national and regional workshops.

American MEDICAL Association

515 N Dearborn St Chicago, IL 60610 (800) 262-3211 (voice) (312) 464-5000 (voice) (312) 464-4184 (fax) Represents physicians, academicians, medical students and representatives of organized medicine.

American MENTAL HEALTH COUNSELORS Association

5999 Stevenson Ave Alexandria, VA 22304 (703) 823-9800 (voice) (703) 823-6862 (TTY) (703) 823-0252 (fax) A division of the American Association for Counseling and Development. Provides support to professional mental health counselors. Sets service training standards and advocates on legislative issues.

American Network of COMMUNITY OPTIONS AND RESOURCES

4200 Evergreen Ln, Ste 315
Annandale, VA 22003
(703) 642-6614 (voice)
(703) 642-0497 (fax)
Represents about 500 private
service provider companies for
people with developmental disabilities, mental illness and other
disabilities. Provides training and
educational opportunities for its
members.

American NURSES Association 600 Maryland Ave SW, Ste 100W Washington, DC 20024-2571 (202) 651-7000 (voice) (202) 651-7001 (fax) Represents more than 210,000 registered nurses. Advances nursing by upholding high standards of practice, promoting the economic and general welfare of nurses in

registered nurses. Advances nursing by upholding high standards oi practice, promoting the economic and general welfare of nurses in the workplace and projecting a positive and realistic view of nursing. Lobbies on health care issues.



American OCCUPATIONAL THERAPY Association

4720 Montgomery Ln
P0 Box 31220
Bethesda, MD 20824
(800) 377-8555 (TTY)
(301) 948-9626 (voice)
(301) 652-7711 (fax)
Accredits educational programs, certifies practitioners and advocates on programs related to national health care issues.
Distributes professional information packets on many subjects.

American ORTHOTIC and PROSTHETIC Association

1650 King St, #500
Alexandria, VA 22314
(703) 836-7116 (voice)
(703) 836-0838 (fax)
Represents manufacturers of orthotic and prosthetic devices and facilities providing prosthetic patient care. Provides a list of schools offering a curriculum in orthotics and/or prosthetics.

American PHYSICAL THERAPY Association

1111 N Fairfax St Alexandria, VA 22314 (800) 999-2782 (voice) (703) 684-2782 (voice) (703) 684-7343 (fax) Accredits academic programs in physical therapy, assists in composing state certification exams and offers educational courses and workshops. Refers people with disabilities to physical therapy facilities.

American PSYCHOLOGICAL Association

750 First St NE
Washington, DC 20002
(800) 336-4980 (voice)
(202) 336-5500 (voice)
Works to advance psychology as a science, a profession and a means of promoting human welfare. Promotes policy, research and standards of ethical conduct and education.

American REHABILITATION COUNSELING Association

5999 Stevenson Ave
Alexandria, VA 22304
(703) 823-9800 (voice)
(703) 823-0252 (fax)
Division of the American
Counseling Association (ACA).
Seeks to improve rehabilitation
counseling services to people with
disabilities. Supports and participates in ACA's accreditation.

American SCHOOL COUNSELOR Association

5999 Stevenson Ave Alexandria, VA 22304 (703) 823-9800 (voice) (703) 823-6862 (TTY) (703) 823-0252 (fax) Provides support to counselors, counseling and guidance directors, supervisors, administrators and counselor educators.

American SCHOOL HEALTH Association

Association
7263 State Rt 43
PO Box 708
Kent, OH 44240
(216) 678-1601 (voice)
(216) 678-4526 (fax)
Promotes comprehensive school health programs. Offers free publication catalog.

American SPEECH-LANGUAGE-HEARING Association

HEARING Association
10801 Rockville Pike
Rockville, MD 20852
(800) 638-8255 (V/TTY)
(301) 897-5700 (V/TTY)
(301) 571-0457 (fax)
Certifying body for professionals in speech, language and hearing therapy. Accredits graduate, clinic and hospital programs in speech-language pathology and audiology. Provides free information, refeirals and consumer-oriented publications through toll-free (800) phone number.

Association for CHILDHOOD EDUCATION International

11501 Georgia Ave, Ste 315
Wheaton, MD 20902
(800) 423-3563 (voice)
(301) 942-2443 (voice)
(301) 942-3012 (fax)
Concerned with development,
growth and education from infancy through early adolescence.
Sponsors annual conference.
Offers about 100 books, pamphlets, videos and audiotapes
through publication catalog.

Association for DRIVER EDUCATORS for the Disabled

PO Box 49
Edgerton, WI 53534
(608) 884-8833 (voice)
(608) 884-4851 (fax)
Seeks to improve driver education and evaluation for people with disabilities. Provides information on teaching techniques, assessment methods and technological developments.

Association of Schools of ALLIED HEALTH Professionals

1730 M St NW, Ste 500
Washington, DC 20036
(202) 293-4848 (voice)
(202) 293-4852 (fax)
Represents health care professionals and educators in wide range of fields including corrective, occupational, physical and recreational therapies. Provides information on allied health, innovative projects and individual expertise. Sponsors annual conference, leadership workshops, fellowships and a world congress.

Association of Specialized and Cooperative LIBRARY Agencies

American Library Association
50 E Huron St
Chicago, IL 60611
(800) 545-2433 (voice)
(312) 944-6780 (voice)
(312) 944-7298 (TTY)
(312) 280-3255 (fax)
Represents librarians serving
communities and special populations, including people with physical and mental disabilities.
Provides printed information to
libraries interested in developing
services for people who are blind
or who have mental retardation.

Association on HIGHER EDUCATION and Disability

PO Box 21192
Columbus, OH 43221
(614) 488-4972 (V/TTY)
(614) 488-1174 (fax)
Committed to full participation in higher education for people with disabilities. Sponsors annual conference and publishes material for service providers. Maintains resume databank of people with disabilities seeking employment.

Council for EXCEPTIONAL CHILDREN

1920 Association Dr Reston, VA 22091 (703) 620-3660 (voice) (703) 264-9494 (fax) Monitors and analyzes policies concerning children and youth with disabilities and children and youth who are gifted. Offers publications on special education, disability awareness, child abuse, recreation, parent-professional cooperation, career and vocational education and public policy.

National Association for MUSIC THERAPY

8455 Colesville Rd Silver Spring, MD 20910 (301) 589-3300 (voice) (301) 589-5175 (fax) Approves university curricula for music therapy programs, approves clinical facilities for training music therapists, certifies and registers professionals and provides technical assistance to researchers.

National Association for PERINATAL ADDICTION

Research and Education
200 N Michigan Ave, 3rd Fl
Chicago, IL 60601
(312) 541-1272 (voice)
(312) 541-1271 (fax)
Addresses perinatal addiction and
the long-term outlook for children
exposed in utero to illicit drugs.
Provides national network for
exchange of information, provides
education, coordinates research
and translates current research
into public education programs
and public health policy.

National Association for the EDUCATION OF YOUNG CHILDREN

1509 16th St NW
Washington, DC 20036-1426
(800) 424-2460 (voice)
(202) 232-8777 (voice)
(202) 328-1846 (fax)
Represents 90,000 early childhood professionals and others
dedicated to improving the quality
of early childhood education programs for children birth through
age eight. Accredits early childhood programs. Offers books,
brochures, posters and videos.

National Association of DEVELOPMENTAL DISABILITIES COUNCILS

1234 Massachusetts Ave NW, Ste 103 Washington, DC 20005 (202) 347-1234 (voice) (202) 347-4723 (fax) Promotes development of public policy for community integration and services to people with developmental disabilities through developmental disabilities councils in states and territories.



National Association of MEDICAL EQUIPMENT SERVICES

625 Slaters Ln
Alexandria, VA 22314-1176
(703) 836-6263 (voice)
(703) 836-6730 (fax)
Represents more than 2,000
home medical equipment and
rehabilitation technology suppliers.
Promotes access to quality home
medical equipment services and
rehabilitation/assistive technology.

National Association of PRIVATE SCHOOLS for Exceptional Children

1522 K St NW, Ste 1032 Washington, DC 20005 (202) 408-3338 (voice) (202) 408-3340 (fax) Promotes the role of private special education. Serves as national voice regarding policies that affect children and youth with disabilities.

National Association of REHABILITATION FACILITIES

1910 Association Dr Reston, VA 22091 (800) 368-3513 (voice) (703) 648-9300 (voice) (703) 648-0346 (fax) Advocates on behalf of rehabilitation services to people with disabilities. Provides field services and technical assistance to members and others. Conducts research, sponsors educational forums and develops policy.

National Association of SOCIAL WORKERS

750 First St NE, Ste 700
Washington, DC 20002
(800) 638-8799 (voice)
(202) 336-8310 (fax)
Proposes and promotes sound
public policies and programs
aimed at meeting human needs
and improving quality of life.

National Association of STATE DIRECTORS OF DEVELOPMEN-TAL DISABILITIES SERVICES

113 Oronoco St Alexandria, VA 22314 (703) 683-4202 (voice) Facilitates exchange of information among its 53 state/territorial mental retardation program directors on providing care and treatment for people with mental retardation.

National Association of STATE DIRECTORS OF SPECIAL EDUCATION

1800 Diagonal Rd, Ste 320
Alexandria, VA 22314
(703) 519-3800 (voice)
(703) 519-7008 (TTY)
(703) 519-3808 (fax)
Represents personnel from state
education agencies who have
legal responsibility for the administration and supervision of special
education programs in public
schools. Assists local, state and
national communities in promoting
and enhancing special education.

National EDUCATION Association

Association
1201 16th St NW
Washington, DC 20036
(202) 833-4000 (voice)
(202) 822-7767 (fax)
Informs its members about the
Individuals with Disabilities
Education Act (IDEA). Members
receive a teacher's guide to IDEA
and information on training to help
regular teachers integrate students with and without disabilities.

National THERAPEUTIC RECREATION Society

2775 S Quincy St, Ste 300
Arlington, VA 22206
(703) 820-4940 (voice)
(703) 671-6772 (fax)
Committed to recreation and leisure services for all. Offers professional assistance, publications and conferences.

Registry of INTERPRETERS FOR THE DEAF

8719 Colesville Rd, Ste 310 Silver Spring, MD 20910 (301) 608-0050 (V/TTY) (301) 608-0508 (fax) Certifies interpreters (American Sign Language/Spoken English) and transliterators (Signed English/Spoken English). Maintains and promotes code of ethics and operates grievance system. Sells annual directory listing certified interpreters and transliterators. Provides information on finding and using interpreters, careers in interpreting and professional development.

RESNA

1700 N Moore St, Ste 1540 Arlington, VA 22209 (703) 524-6686 (voice) (703) 524-6639 (TTY) (703) 524-6630 (fax) Represents rehabilitation professionals. Seeks to transfer science, engineering and technology to the needs of people with disabilities. Sponsors annual conference and publishes books and a video.

SCIENCE Association for Persons with Disabilities

c/o Dr Janet Davies
Colorado Christian University
180 S Garrison St
Lakewood, CO 80226
(303) 238-5386 (voice)
(303) 274-7560 (fax)
A division of the National Science
Teachers Association. Promotes
science and encourages the
development of curricula for people with disabilities. Provides
information about teaching science to people with disabilities.

World Association for INFANT MENTAL HEALTH

ICYF
Kellogg Ctr, #27
Michigan State University
East Lansing, MI 48824
(517) 432-3793 (voice)
(517) 432-3694 (fax)
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Zero to Three/National Center for CLINICAL INFANT PROGRAMS

2000 14th St N, #380
Arlington, VA 22201-2500
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(703) 528-0419 (TTY)
(703) 528-6848 (fax)
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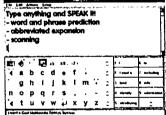
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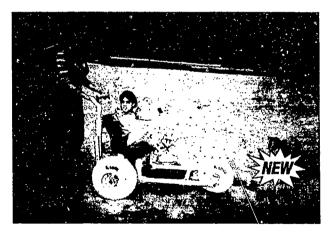
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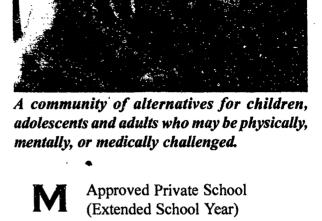
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Wayland Road, Berwyn, PA 19312 Phone (610) 353-1726 Fax (610) 353-8528

Circle # 69

1994 EXCEPTIONAL PARENT TOPICAL INDEX

This is an index of articles which appeared in 1994 monthly issues of Ecceptional Parent. Although all arti-
cles are of interest to both educators
and health care professionals, those
articles of special interest to these two
groups of readers have been marked
(= educators;) = health care professionals; $= both)$

ABLEDATA (See also: New Products)
The ABLEDATA Database
of Assistive TechnologyMar 56
Accessibility
Buying and Converting:
Vans and lifts Dec 45
Environmental ControlsNov 51
Special BathroomsAug 45
Step by Step: Creating no-step
entrancesOct 59 ADA (See: Americans with Disabilities Act, The)
ADD (See: Attention Deficit Disorder)
Adolescence (See: Teens) Advocacy (See also: National Parent Network
on Disabilities)
From Rage to Reform: What Parents
Say About AdvocacyMay 49
The Parent and Professional Aliiance
ProgramAug 26
Adrenoleukodystrophy (See: Leukodystrophy)
Agenesis of the Corpus Callosum
If I Could Give the World a GiftDec 68
Angelman Syndrome
Crying Can Make You a Better Man May 47
Alliance for Technology Access
(See also: Technology)
Alliance for Technology Access
CentersNov 26
Alliance For Technology Access
UpdateNov 26
Computer Resources for People
with DisabilitiesSep 61, No 29
Real People, Real Technology,
Real SolutionsNov 20
Americans with Disabilities Act, The
Loving Justice: The ADA and
the Religious CommunityDec 43
Arts, The
The Arts and Disability
The Sky is the Limit
Ask The Doctor ◆ Flu & Preumonia VaccinesNov 19
♣ IncontinenceJul 50♣ IrritabilityOct 16
Nutrition and GrowthAug 18
Respiratory Problems
Transition to Oral Feedings;
FelbamateDec 50
Assistive Technology (See: Technology)
Attention Deficit Disorder
(See also: Learning Disabilities)

Augmentative and Alternative
Communication Devices
(See also: Communication, Technology)
O Augmentative and Alternative Communication DevicesJun 51
Augmentative and Alternative
Communication Devices,
Manufacturers ofJun 51
HEALTH INSURANCE TROUBLESHOOTER:
Coverage for Augmentative
Communication DevicesNov 68
Real People, Real Technology,
Real SolutionsNov 21
ROLE MODELS: Walsh, Robert
A journey to communication with
assistive technologyNov 37
Toc Few Exceptions to the RuleNov 31
Autism
Brain Differences in AutismMar 66 As Franchiscol Visit & Discourse Ass 85
An Exceptional Visit to DisneyApr 25
The First Day of SchoolSep 35
Not For a Nickel and a DimeJul 42
Oh Brother!Jul 68
Song of LightNov 45
Bathrooms
Bathroom Access Aids,
Manufacturers ofAug 47
Special BathroomsAug 45
Bereavement
Remembering DanielJun 68
Remembering JordieOct 4
Blindness (See: Visual Impairments)
Books (See also: Media)
🛳 Count Us In: Growing up
with Down syndromeApr 17
Honor Thy SonJul 44
SIBSHOPS: Workshops for
Siblings of Children with
Special NeedsSep 47
• When Young Children are InjuredDec 56
Brooks, Garth
Standing Outside the Fire
music videoSep 72
Camps, Summer
Selecting aMar 55
Cargnel, Stefano (see Role Models)
Cerebral Palsy
All in the FamilyApr 22
The Biggest GameOct 55
A Date to RememberJul 24
Dear TimmySep 53
◆ A Few Miles on the OI' RockerDec 18
Grieving a DreamOct 26
I'm Bryan's Dad and Part
of His TeamFeb 28
Real People, Real Technology,
Real SolutionsNov 20
ROLE MODELS: Rousso, Harilyn
Sex, Lives and DisabilityOct 23
ROLE MODELS: Walsh, Robert
A journey to communication
with assistive technologyNov 37
₹ Too Few Exceptions to the RuleNov 31

Ch	ild Care	
٠	What Happens Next?	.Sep 80
	Who Cares for the Children with	
	Chronic Illness and Disability?	Sep 77
	A Working Together Checklist (Providence of the Checklist)	
0 1-	Family & Early Intervention)	Sep 80
Un	ildren's Page Friends and Classmates	Eob 61
	Having a Sister with a Disability	FU 01 Anr 68
	If I Could Give the World a Gift	Apr 00 Dec 68
	Joseph	
+	Living with Moebius Syndrome	
	My Brother	May 68
	My New Brother	0ct 84
	My Twin Sister	
	Oh Brother!	Jul 68
Ch	Remembering Daniel ronic Illness and Disability,	Jun bช
UII	Center for Children with	
+	A.	Mar 51
-	Children's Health Notes	
	ffin-Lowry Syndrome	сор
	My Brother	May 68
	llege Education	
	ROLE MODELS: Kemp, John	
_	Part II: Meeting the public	Aug 34
	R ROLE MODELS: Heumann, Judy Part I: Growing up with	
	a disability	Feb 30
7	ROLE MODELS: Miliar, Carrie	60 00
_	Harvard student-athlete talks	
	about growing up deaf	Jun 18
2	R ROLE MODELS: Nemeth, Abraham	
	Creator of Nemeth code	
	for Braille mathematics	Sep 31
2	R ROLE MODELS: Walsh, Robert	
	A journey to communication with assistive technology	Nov 37
C	ommunication (See also: Technolog	1404 37
	Augmentative and Alternative	"
	Communication Devices	Jun 51
0	Augmentative and Alternative	
	Communication Devices,	
	Manufacturers of	Jun 51
O	HEALTH INSURANCE TROUBLESHOOTER:	
	Coverage for Augmentative Communication Devices	Nov 60
4	Real People, Real Technology,	1107 00
-	Real Solutions	. Nov 21
•	ROLE MODELS: Walsh, Robert	
	A journey to communication	
	with assistive technology	Nov 37
	Too Few Exceptions to the Rule	Nov 31
C	omputers (See: Technology,	
•	Telecommunications)	na)
	ushions (See: Seating and Position): ycling (See: Recreation)	ig)
U	young (occ. necreation)	
D	ating	
.,	A Date to Remember	Jul 24
	eafness (See Hearing Impairments)	
D	eath (See: Bereavement)	
	ental Care	
+	Growth and Development	0
	Checklist	აცე ნი



🚓 Listening to LearnApr 46

+	Part I: Preventing Dental Disease	
	with Daily Oral CareAug 3	8
+	Part II: Brushing, Flossing and	
	RinsingSep 5	7
+	Part III: A Visit to the DentistOct 6	1
÷	Part IV: Common Pediatric	
•	Dental ProblemsNov 5	ંર
+	Special Children are at	,,
•	Greater RiskAug 3	00
n :		9
	rectories	
5.7	Alliance for Technology Access	
	CentersNov 2	26
0	Augmentative and Alternative	
	Communication Devices,	
	Manufacturers ofJun 5	51
0	Bathroom Access Aids,	
	Manufacturers ofAug	
	Commercial Online ServicesJun 3	37
	Cycle and Cycle Accessory	
	ManufacturersApr !	52
	Disability-Related Electronic Bulletin	
	BoardsJun	43
0	Disability-Related Internet	
_	Mailing ListsJun	42
•	Early Intervention Contact Persons,	_
	State-by-StateFeb	21
	Faith Group Resources	
_	Incontinence Products,	00
•	Manufacturers ofAug	EΛ
_	National Compunity Sites Oct	4Q
7.2	Lekotek and Compuplay SitesOct	40
	Racing Wheelchairs for Children,	۲0
	Manufacturers ofMay	
_	Recreation ResourcesMay	54
.+		40
	ManufacturersFeb	
	Special Olympics State ChaptersMay	
	Travel ResourcesApr	
	Wheelchair ManufacturersMar	3/
D	isability Awareness	
1	All Children BelongJul	36
7	Friends Who Care May 63, Oct	33
	In Defense of My DaughterMar	47
D	own Syndrome	
	Cut From the Same Bolt of Cloth Sep	55
	In Defense of My DaughterMar	47
1	🛪 A Graduation for TwoFeb	25
	Honor Thy SonJul	
	Kate's SongJun	22
1	Making Inclusion WorkSep	43
	Mimi, My FriendAug	23
	My New BrotherOct	84
1	Kingsley, Jason and Mitchell Levitz:	
	Young authors challenge stereotypes	
	and misconceptionsApr	17
	Sense of Humor RequiredApr	
	Standing Outside the Fire music	
	videoSep	72
	arly Intervention	
	A Graduation for TwoFeb	25
	National OverviewFeb	
	Rational OverviewFeb	
7	State-by-State DirectoryFeb	23
		21
	Editorials Light Caro Botom Ech	. 22
	Health Care ReformFeb	
	Inclusion: Rhetoric and RealityApr	
1	Too Few Exceptions to the RuleNov	31

Education (See also: College Education, Educational Choice, Inclusion) 1994 Educational Program
AwardsSep 36–44
All Children BelongJul 36
★ Court Backs Private School Choice Feb 59
name Department of Education Upholds
Right to PrivacyApr 51
nisabilities, Opportunities, Internetworking
& Technology=D0-ITNov 33
🖮 Friends Who CareOct 33
★ Inclusion and IdeologySep 39
nclusion: Rhetoric and RealityApr 39
nclusion: What It Is, What It's Not,
and Why It MattersSep 36
Apr 46



	I	
A Making Inclusion Work	Sep 43	
A National Agenda For Achieving	·	•
Better Results	Sep 41	
⇒ Options		
RESEARCH: Are They Ready to Teach		
Our Kids?	Dec 54	
Role Models: Heumann, Judy		Ι,
Part II: OSERS chief discusses		
her vision for the future	Mar 50	١.
Riding the Bus		
Senate Adopts Dole Amendment	wiuy 72	١.
to GOALS 2000 Bill	Mar 90	'
Students With Disabilities In Regula		ļ
Classes	Feb 59	
Educational Choice	F-1- FO	1
Court Backs Private School Choice		İ
nclusion: Rhetoric and Reality		
ng Options	Jul 55	
Employment		
Career Planning for People with		
Visual Impairments		ĺ
Disability Really Isn't That Romantie		
Environmental Controls (See: Acces	sibility)	Ì
Epilepsy (See: Seizures)		
Fathers' Voices		l
The Biggest Game	0ct 55	1
Crying Can Make You		
a Better Man	May 47	
Dear Timmy		
	•	1

	DreamsApr 44
+	Fathers are Caregivers, Too!Aug 43
+	A Few Miles on the Ol' RockerDec 18
O	I'm Bryan's Dad and Part of His TeamFeb 28
	Not For a Nickel and a DimeJul 42
	Rachel, Say "Hi"Mar 62
	What's a Tough Guy to Do?Jun 45
	A Whole New BallgameNov 55
Fe	minIsm
13	Role Models: Rousso, Harilyn
	Sex, Lives and DisabilityOct 23
٥-	unioning (Con. Donnation)
Gr	rdening (See: Recreation)
Gi	Crying Can Make You a Better ManMay 47
	DreamsApr 44
+	
	Remembering DanielJun 68
	ealth Care, Education
+	The Parent and Professional Alliance
_	ProgramAug 26 A Bit of Teenage SavvyAug 30
	ealth Care, Funding
	Do You Know Who Pays the Bills?Mar 52
He	ealth Care, Policy
+	Collaborating to Influence the
	Health of ChildrenMar 51
	ealth Care, Reform
+	Action AlertFeb 35 Editorial ReportFeb 33
+	
•	and Their FamiliesJun 47
+	Health Care for All-Now or Never! Apr 56
+	Health Care Reform Misses Persons
	with DisabilitiesFeb 41
+	Home Stretch for Health Care
	ReformJun 56
+	One Child's ProfileFeb 42 Riding the Health Care Roller
•	CoasterFeb 36
+	
H	ealth Care, Services
+	
+	
	of ChildrenMar 51
+	Developing a Service Provision Report CardJul 56
+	The Parent and Professional Alliance
	ProgramAug 26
H	ealth Insurance (See also: Health Insurance
_	TROUBLESHOOTER)
4	
n	EALTH INSURANCE TROUBLESHOOTER Coverage for Augmentative Communication
•	DevicesNov 68
4	
4	 Insurance coverage for Incontinence
	ProductsAug 57
4	
4	Finding Your Way Through the
_	Medicaid MazeSep 26 Medicaid and HMOsDec 52
1	learing Impairments
	ROLE MODELS: Miller, Carrie
'	Harvard student-athlete talks
	about growing up deafJun 18



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milet every need.



Circle # 16

1994 INDEX

Heumann, Judy (see Role Models)
Humor
The Dangerous YewJul 20
The HelmetFeb 39 Lost In the Mall!Mar 45
Sense of Humor RequiredApr 32
Sense of number nequiredApr 32
Inclusion (See also: Education, Religion)
All Children BelongJul 36
The First Day of SchoolSep 35
➡ Friends and ClassmatesFeb 61
★ Friends Who CareMay 63, Oct 33
★ Inclusion and IdeologySep 39
finclusion: Rhetoric and RealityApr 39
nclusion: What It Is, What It's Not,
and Why It MattersSep 36
★ Making Inclusion WorkSep 43
A National Agenda For Achieving
Better ResultsSep 41
OptionsJul 55
ROLE MODELS: Kemp, John
Part I: Growing up with inclusionJul 34
Students With Disabilities In Regular
ClassesFeb 59
Income Tax
Guide to PreparingFeb 55
Incontinence
◆ Ask The Doctor: Questions About
IncontinenceJul 50
¹ Incontinence ResourcesAug 50
↑ Incontinence Products,
1

Kemp, John (See: Role Models) **Kingsley, Jason** (See: Role Models)

Insurance (See: Health Insurance)
Irritability (See: Ask THE DOCTOR)

HEALTH INSURANCE TROUBLESHOOTER:

Insurance coverage for

Learning Disabilities	
RESEARCH: Are They Ready to Te	ach
Our Kids?	Dec 54
★ Listening to Learn	Apr 46

Manufacturers ofAug 50

Incontinence Products......Aug 57

Legislation (See also: Health Care,	Reform;
National Parent Network on Disa	bilities)
Crime Bill	Jun 55
Family Support	.Jun 55, 56
Reauthorization of the Individuals	3
with Disabilities Education Ad	ctJun 55
★ Senate Adopts Dole Amendment	
to GOALS 2000 Bill	Mar 80
Lennox-Gastaut Syndrome	
♣ Ack the Doctor: Felhamate	Dec 50

Leukodystrophy ALD—Balancing Hope Against Realth

ALD—Balancing Hope Against
 RealityFeb 53
 What's a Tough Guy to Do?Jun 45

Levitz, Mitchell (See: Role Models)

articles of interest to educators:

- articles of interest to health care professionals:
- o articles of interest to both

Limb Anomalies ➡ Role Models: Kemp, John
Part I: Growing up with inclusionJul 34
Part II: Meeting the publicAug 34
Media
Computer Resources for People
with DisabilitiesSep 61
Honor Thy SonJul 44 Loving Justice: The ADA and the
Religious CommunityDec 43
That All May WorshipDec 43
Medicaid (See: HEALTH INSURANCE
Troubleshooter) Miller, Carrie (See: Role Models)
Minorities
Parent Case Management for
People of ColorAug 56 Mobility (See also: Wheelchairs)
Buying and Converting: Vans
and liftsDec 45
Doing What Works BestMar 18 Least to the Mall.
Lost In the Mall! Mar 45 Powered Mobility for Your Child?Mar 33
Wheeled Mobility Selection: A Guide
for ParentsMar 23
Moebius Syndrome ◆ Living with Moebius SyndromeAug 68
Living with Moebius SyndronieAug 08
National Parent Network on Disabilities
(NPND) NetworkingFeb 41
NetworkingApr 55
NetworkingJun 55
NetworkingAug 55
NetworkingOct 77 Nutrition (See: Ask the Doctor)
·
Opinion (See: Editorials, Point of View)
Parent-Professional Relationships
Developing a Service Provision
Report CardJul 56
O I'm Bryan's Dad and Part of His TeamFeb 28
◆ Fathers are Caregivers, Too!Aug 43
 The Parent and Professional Alliance
ProgramAug 26 Parenting (See also: Father's Voices)
All in the FamilyApr 22
Cut From the Same Bolt of Cloth Sep 55
The Dangerous YewJul 20
 ★ Disability Really Isn't That RomanticJul 46 ◆ Doing What Works BestMar 18
An Exceptional Visit to DisneyApr 25
A Father's GiftMay 19
The First Day of SchoolSep 35
The First TimeJul 31 For the Love of PeterDec 41
Forrest Pumps: A sound-activated
water gun needs no adaptations. Oct 40
A Graduation For TwoFeb 25 Grieving a DreamOct 26
The HelmetFeb 39
In Defense of My DaughterMar 47

Kate's SongJun 22
★ Listening to LearnApr 46
Lost In the Mail!Mar 45
Mimi, My FriendAug 23
Peter's GardenMay 22
Riding the BusMay 42
 Riding the Health Care
Roller CoasterFeb 36
Sense of Humor RequiredApr 32
Song of LightNov 45
Play (See: Toys)
Point Of View
n Disability Really Isn't That RomanticJul 46

Our Civil War Over Residential CareMar 72 Positioning (See: Seating and Positioning) Products, New		
0	New Products	Apr 54
0	New Products	May 65
0	New Products	Jun 65
0	New Products	Jul 65
0	New Products	Aug 64
0	New Products	Sep 76
0	New Products	Oct 80
0	New Products	Nov 73
O	New Products	Dec 47

New Products: Toys......Oct 52

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- Neonatal Intensive Care
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- Pediatric Endocrinology
- Pediatric Gastroenterology
- Pediatric Infectious Diseases
- Pediatric Intensive Care
- Pediatric Nephrology

- Pediatric Neurology
- Pediatric Nutrition Program
- Pediatric Ophthalmology
- Pediatric Pulmonology
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- Pediatric Subspecialty Clinics
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- Pediatric Urology
- Perinatology
- Regional Perinatal Center
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Directory of Advertisers

Circle	Advertiser	Page
103	AccessAble Environments	74
2	Adaptive Design Labs	98
32	Adaptive Design Shop	.111
175	American Standard	
	Apple Computer	
118	Aquatic Therapy	
75 62	ARC/Otsego	,112 71
111	Ball Dynamics	
39	Barrier Free Lifts	44
10	Berkshire Meadows	.107
84	Bethesda Lutheran Home	.132
112	Braun Corp	
113	Braun Corp.	11
6	Bruno Independent Livings Aids	
60 61	Bustop Alert	oz 30
25	Charles C. Thomas	
38	Child Quest	
11	Children's Specialized Hospital	
146	Chrysler	
151	Columbia Medical	
150	Columbia Medical	
138 126	Consumer Care	
73	Crotched Mountain Rehab	
119	Crow River Industries	
124	Crystal Springs School	
74	Cumberland Hospital	
107	Devereux Foundation	
105 141	Diestco Manufacturing	
109	Don Johnston	
79	Elwyn	
123		
31	Estate Planning	
106		90
450	Expocon Management Association.	
156		
5 132		
135		
168		
	General Motors	73
13		
36		
44 166	, ,	
14	·	
3		
77	HMS School	51
101		
90		
92	•	
145 122	9	
110		
42		
26	JA Preston	C4
56	,	
147	,	
176 140		
146	Just Two Bikes	104

Circle	Advertiser	Page
	Kaleidoscope	83
70	Kennedy Krieger	
50	Key Concepts	88
48	Keystone City Residence	
98	Kid-Kart/Kid Care	
177	kidTECH/SoftTouch	
133 18	Kimberly-Clark	
163	Kotton & Koala	
45	Laureate Learning	
24	League School	
117	Lubidet	
1	M.J. Markell Shoe	56
16	Marblesoft	
78	Martha Lloyd Community Services	
131	Maryland Insurance Group	
93	Med Group	C3
83	Meeting Street Center	
69	Melmark	
76	NARIC New England Ctr for Autism	
70 21	New England Villages	
68	North Coasta! Medical	104
139	NR Labs	
165	Olsten Kimberly QualityCare	4
184	Oralgiene	
12	Plum Enterprises	3
59	Prentke Romich	
89	Principal Business Enterprises	
49	Pro Battery Specialists	
80 63	R.J. Cooper & Assoc	
37	Rhamdec	
85	Ricon	
41	Rifton	
171	Rock N' Roll	41
47	Roleez Wheel System	
161	Sentient Systems Technology	
51	Snug Seat	
104 130	Sony Electronics	
167	Special Design	
22	Sportime	
162	St. Coletta (MA)	
17	St. Joseph's Hospital &	
	Medical Center	
4	Stewart Home School	
164	Stroller Pack	
134	Taylor Made	
121 136	Temasek Telephone	
40	Tiger Communications	
20	TMI	
19	TMI	
160	Toys for Special Children	
125	Treadle Power	
46	Triaid	
33	Vail Products	
102 43	Vantage Mini VansVisible Ink	
43 108	Voorhees Pediatric Facility	
91	Willow River Farms	
72	Woodbury Products	
_	-	

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115

204 205

293 294 295 296

112

141 142

201 202

260 251

	C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young autility with disabilities or special health care needs? Tyes Till No
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91 92 93 94 95 96 97 98 99 100 101 102 103 104 105 121 122 123 124 125 126 127 128 129 130 131 132 133 134 135 151 152 153 154 155 156 157 158 159 160 161 162 163 164 165 181 182 183 184 185 186 187 188 189 190 191 192 193 194 195 211 212 213 214 215 216 217 218 219 220 221 222 223 224 225 241 242 243 244 245 1246 247 248 249 250 121 252 253 254 255	46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 76 77 78 79 80 81 82 83 84 85 86 87 88 89 90 106 107 108 109 110 111 112 113 114 115 116 117 118 119 120 136 137 138 139 140 141 142 143 144 145 146 147 148 149 150 166 167 168 169 170 171 172 173 174 175 176 177 178 179 180
2/1 2/2 2/3 2/4 2/512/6 2/7 2/8 2/9 2801281 282 283 284 203	1200 201 200 203 2301231 292 233 234 2331233 231 230 233 300
	t you, please circle the number that appears on the advertisement or listing in this issue.
*CIRCLE NUMBERS: To obtain FREE information about those products or services that interes Expiration date: December 31, 1995.	t you, please circle the number that appears on the advertisement or listing in this issue.
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CIRCLE NUMBERS: To obtain FREE information about those products or services that interes Expiration date: December 31, 1995. Table Comparison Comparison	Free product & service information order card FAX this card to 413-637-4343 for quicker response C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disclosure or special health care needs? If the care of children or young adults with disclosure or special health care needs? If the care of children or young adults with disclosure or special health care needs? If the care of children or young actives all Physician therapist of Special Pathologist, Audiologist
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CIRCLE NUMBERS: To obtain FREE information about those products or services that interes Expiration date: December 31, 1995. Table Comparison Comparison	Free product & service information order card FAX this card to 413-637-4343 for quicker response C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young addrs with directions or special health care needs? In the Care of children or young addrs with directions or special health care needs? In the Care of children or young addrs with directions or special health care needs? In the Care of children or young addrs with directions or special health care needs? In the Care of children or young addrs with directions or special health care needs? In the Care of children or young addrs with directions or special health care needs? In Speech Pathologist, Audiologist of the your an EDUCATOR? In the Care of Ca
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185 186

247

273 274 275 276 277 278 279 280 281 282

248 249

124 125

213 214 215 243 244 245

 283 284 285 286 287 288 289 290 291 292

ذ7

103 104

191 192





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Pyruvate Dehydrogenase Deficiency
Remembering DanielJun 68
Recreation (See also: Arts, Vacation)
★ The Arts and DisabilityMay 33
CyclingApr 52
Gardening is for Everyone!May 24
A Father's GiftMay 19
Fishing Has No Boundaries
★ Meeting the Challenge: The President's
Council on Physical FitnessMay 38
Peter's GardenMay 22
Racing Wheelchairs for Children May 52
Racing Wheelchairs for Children,
Manufacturers ofMay 52
Recreation ResourcesMay 54
ROLE MODELS: Cargnel, Stefano:
Becoming a contenderMay 28
ROLE MODELS: Miller, Carrie
Harvard student-athlete talks
about growing up deafJun 18
Selecting A Summer CampMar 55
Special Olympics State ChaptersMay 57
The Sky is the Limit
Standing Outside the Fire
music videoSep 72
Religion
Advocating for AccessDec 33
Catholic Life for Children
with DisabilitiesDec 26
Faith Group ResourcesDec 38
For The Love of PeterDec 41
A Jewish Education For Every ChildDec 29
Loving Justice. The ADA and the
Religious Community
Religious Participation For AllDec 22
Role Models: Mulzet, Jimmy
A dream of meeting the Pope
comes trueDec 35
That All May WorshipDec 43
Toward a More Inclusive Protestant
Sunday SchoolDec 31
Vignettes: Stories of individual children's
religious participationDec 23–40
Research
Adrenoleukodystrophy—Balancing Hope
Against RealityFeb 53
Are They Ready to Teach Our Kids?Dec 54
Brain Differences in AutismMar 66
From Rage to Reform: What Parents
Say About AdvocacyMay 49
Residential Care (See also: Educational
Choice)
Our Civil War Over Residential CareMar 72
Respiratory Problems (See: Ask the Doctor)
Role Models
★ Cargnel, Stefano: Becoming
a contenderMay 28
Heumann, Judy
Part I: Growing up with
a disabilityFeb 30
a diodoliky

Part II: OSERS chief discusses
her vision for the future Mar 59
🚓 Kemp, John
Part I: Growing up with inclusion Jul 34
Part II: Meeting the publicAug 34
Kingsley, Jason and Mitchell Levitz:
Young authors challenge stereotypes
and misconceptionsApr 17
A Miller, Carrie: Harvard student-athlete talks
about growing up deafJun 18
Mulzet, Jimmy: A dream of meeting
the Pope comes trueDec 35

 Nemeth, Abraham: Creator of Nemeth code for Braille mathematicsSep 31 Rousso, Harilyn: Sex, Lives and
DisabilityOct 23
Malsh, Robert: A journey to communication
with assistive technologyNov 37
Rousso, Harilyn (See: Role Models)
Rubinstein-Taybì Syndrome
Having a Sister with a DisabilityApr 68

School (See: College Education, Education, Educational Choice, Inclusion)

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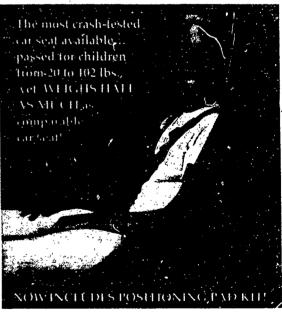
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articles of interest to educators;

articles of interest to both

articles of interest to health care professionals,

Schools, Private (See: Educational Cho	nica I
Residential Care)	ilce,
Seating and Positioning	-
Cushions, Directory of	
Manufacturers	.mar 4 i
Purchasing Seating Equipment:	5 , 45
Tips for Parents	.Fed 45
 Seating and Positioning Equipment, 	
Directory of Manufacturers	Feb 46
Seizures	
Ask the Doctor: Felbamate	
The First Time	Jul 31
Sexuality	
A Charting the Course	Jul 53
★ Living the Course	Jul 54
ROLE MODELS: ROUSSO, Harilyn	
Sex, Lives and Disability	0ct 23
Sibling, Death of	
Remembering Daniel	Jun 68
Siblings	
Having a Sister with a Disability	Apr 68
If I Could Give the World a Gift	Dec 68
Information Needs of Siblings	Dec 49
Joseph Nov 76	
Mimi, My Friend	Aug 23
More Sibling Concerns	Nov 49
My Brother	
My New Brother	Oct 84
My Twin Sister	Mar 78
Oh Brother!	
Remembering Daniel	
SIBSHOPS: Workshops for Siblings	
of Children with Special Needs.	Sen 47
Sibling Concerns	Oct 53
Social Skilis	001 33
A Date to Remember	lul 24
★ Living the Course	
ROLE MODELS: Rousso, Harilyn	Jul 54
	0-4-02
Sex, Lives and Disability	001 23
Special Olympics	
(See: Directories, Recreation)	
Spina Bifida	14- 40
Doing What Works Best	Mar 18
One Child's Profile	Feb 42
Sports (See: Recreation)	
SSI Benefits	
n Disability Really Isn't That Romantic	
Positive SSI Stories	Aug 55

Step-Families	1
My New Brother	Oct 84
my non broater minimum	
Technology (See also: Telecommunicat	ions)
The ABLEDATA Database of	,
Assistive Technology	.Mar 56
Alliance for Technology Access	
Centers	Nov 26
Alliance For Technology Access	
Update	Nov 26
Computer Resources for People	
with DisabilitiesSep 61,	
nternetwo	orking
& Technology=D0-IT	.Nov 33
HEALTH INSURANCE TROUBLESHOOTER:	
Coverage for Augmentative Communication Devices	Nov. CO
communication Devices	NOV DB
Real Solutions	Nov 20
ROLE MODELS: Walsh, Robert	1404 20
A journey to communication	
with assistive technology	Nov 37
Technology Resources	
Too Few Exceptions to the Rule	Nov 31
Teens	
A Bit of Teenage Savvy	Aua 30
A Date to Remember	
★ Charting the Course	
Disabilities, Opportunities, Internetw	orkina
& Technology=DO-IT	Nov 33
A Father's Gift	May 19
★ Living the Course	Jul 54
ROLE MODELS: Cargnel, Stefano:	
Becoming a contender	May 28
ROLE MODELS: Miller, Carrie	
Harvard student-athlete talks	1 . 40
about growing up deaf	
★ Youth Connections	JUI 53
Telecommunications (See also: Tech Commercial Online Services	lun 27
Cruising the Internet	
Disability-Related Electronic Bulletin	บนเ งฮ า
Boards	
Disability-Related Internet Mailing	
Lists	lun 42
Disabilities, Opportunities, Internety	vorkina
& Technology=DO-IT	Nov 33
Exceptional Parent eWorld forum	





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Getting Started with
TelecommunicationsJun 30
Parents OnlineJun 27
Vignettes: Stories of individual
online parentsJun 28-44
Theater (See: Arts, The)
Toys
The Battery InterupterOct 38
Forrest Pumps: A sound-activated water
gun needs no adaptationsOct 40
★ Lekotek Puts Possibilities into PlayOct 46
★ Lekotek and Compuplay SitesOct 48
★ New Products: ToysOct 52
★ Ordinary Toys for Kids with Special Needs
Part IOct 42
Part IINov 42
↑ Toy catalogsNov 71 ↑ Toys For Every ChildOct 36
Toys For Every ChildOct 36
★ USA Toy Library AssociationOct 49
Transition (See also: Teens)
★ Charting the CourseJul 53
Travel (See: Vacation)
Trisomy 18
Joseph Nov 76
Tuberous Scierosis
◆ Tuberous Sclerosis Gene IdentifiedFeb 53
Vacation
Accessible OrlandoApr 26
All in the FamilyApr 22
An Exceptional Visit to DisneyApr 25
Travel ResourcesApr 28
Visual Impairments
The Dangerous YewJul 20
Peter's GardenMay 22
ROLE MODELS: Nemeth, Abraham:
Creator of Nemeth code for
Braille mathematicsSep 31
Walsh, Robert (See: Role Models)
Wheelchair Sports (See also: Recreation)
CyclingApr 52
ROLE MODELS: Cargnel, Stefano:
Becoming a contenderMay 28
Wheelchair Tennis ChampionshipsDec 57
Racing Wheelchairs for Children May 52
Wheelchairs (See also: Mobility)
+ Choosing aMar 23
 Cushion Manufacturers, Directory of Mar 41
Halloween Magic: Making a wheelchair
part of a costumeSep 50
♣ HEALTH INSURANCE TROUBLESHOOTER:
Funding Power WheelchairsOct 20
◆ Manufacturers, Directory of
◆ PoweredMar 33
Racing Wheelchairs for Children May 52
Racing Wheelchairs for Children,
Manufacturers ofMay 52
4

- articles of interest to educators;
- articles of interest to health care professionals;

Youth with Disabilities, National Center for A Youth Connections......Jul 53

o articles of interest to both

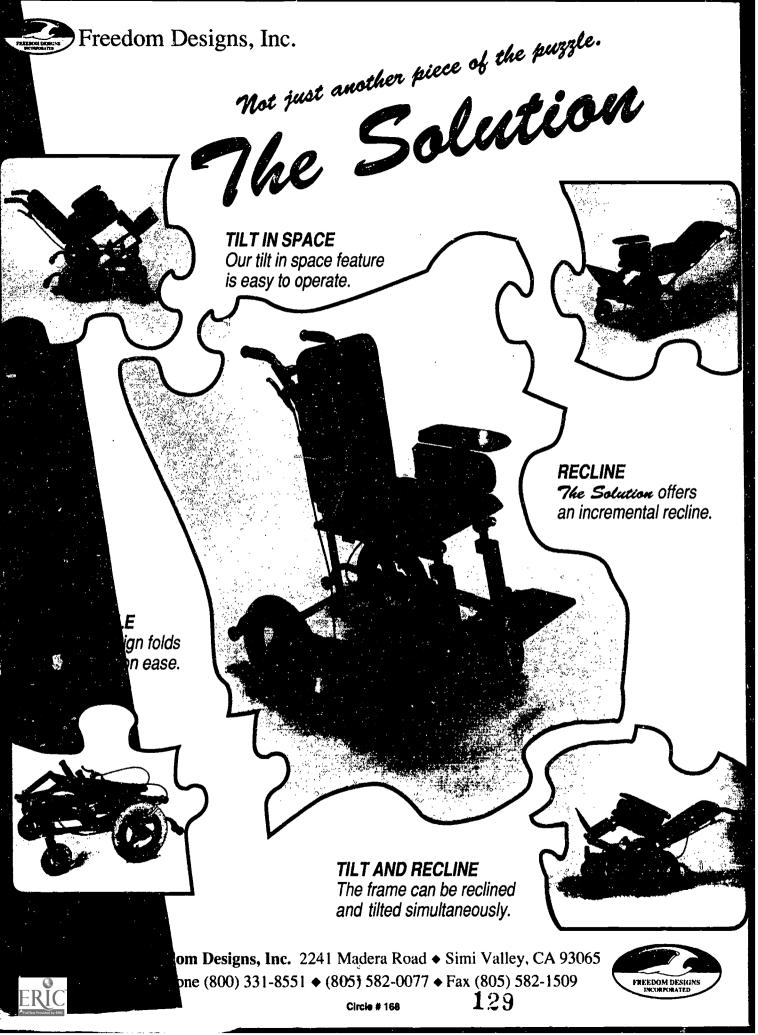
1994 INDEX

1994 SEARCH AND RESPOND INDEX

	•	
Topic ADHD, Community involvement and		Respond Nov
Adoptive parents	Aug	
Angelman syndrome		•
Aniridia, bilateral		Sep
Arnold-Chiari malformation		
Arthrogryposis multiplex congenita	Mar	
Asperger's syndrome/		•
Landau-Kleffner syndrome (1	Nov/Dec 9	3)Mar
Augmentative communication aids		
Autism, Puberty and	. (Sep 93).	Feb
Autism/PDD, Muscular dystrophy and		Test
Band heterotropia		Jui
Benign congenital hypotonia	Apr	Aug
Blind, Down syndrome and		_
Bloom syndrome		
Books for parents	Apr	
Brain stem, Low		
Catheterization?	Sep	
Catheterization help		
Celiac sprue		Jun
Cerebral arteriovenous malformation		_
Children, two non-ambulatory		
Chondrodysplaysic punctata		Jui
Chromosome 8, Partial deletion of		
Chromosome 10 inversion.		
Chromosome 22, Ring		
Chromosome 48,XXXX	Mar	
Chromosome 48,XXXY		
Chromosome translocation		Jul
Chromosome XXXXX		Feb
Cogan syndrome		
College with personal attendant		Apr, May
Communication, frustration with	Nov	
Community involvement, ADHD and	Sep	Nov
Cytomegalovirus, Congenital		
Darrow syndrome		
Daycare Deafness, motor impairments and		
DiGeorge syndrome	Jun	Aug
Disabilities, Multiple, Unsure about future	Sep	
Disabilities, Parents with		
Disabilities, Single parent with) Apr
Disabilities, Severe		May In
Disability awareness in public schools	Peb Oct	May, Jui
Down syndrome and blind	Nov	
Down syndrome and feeling "different"	Jun'	Aug
Down syndrome and non-verbal	Oct	Dec
Down syndrome, Two children with		
Drooling		
Early myoclonic encephalopathy syndrome,	Wai	
Nonoxynol-9 spermicide and	(Oct 93) Feb
Encephalocele and Meckel syndrome	Apr	
Epidermal nevus syndrome, liponias and		
Failure to thrive, Non-organic		
Fiber-type disproportion, Congenital) Eals
G-Tube with internal disk	May)reb
Guillain-Barre syndrome, Chronic	Dec	
Herpes encephalitis, neonatal	Sept	
Holoprosencephaly, Semilobar	(Nov/Dec	93) Feb
Hypotonia, Benign congenital	Apr.	Aug
Inchisive school districts (New England)	Mar.	Jun
Inclusion, Feeling "different"		Aug
Infantile spasms		
Insurance	Nov	
Ischemic strokes	Apr .	Jul
Jacobsen's syndrome	Mar	. ,
CD.		4

Johanson-Blizzard syndrome	Sen
Kabuki makeup syndrome	Aug
Klinefelter syndrome/48,XXXY	Oct
Landau-Kleffner syndrome/Asperger's	001
syndrome :	(Nov/Dec 93) Mar
Langer-Giedion syndrome	
Learning disabilities, Dealing with the system.	
Learning disabilities, Parents with	
Leber's congenital amaurosis	
Lennox-Gastaut syndrome	
Lipomas. Epidermal nevus syndrome and	
Lipomyelomeningocele	
Loud noises in public	
Macroglossia	
Meckel syndrene, Encephalocele and	Anr
Monsomy 5 /Trisomy 4p	
Motor impairments, Deafness and	
Multiple disabilities, Unsure about future	
Muscular dystrophy, Autism/PDD and	Feb
Myotubular myopathy, X-linked	
Nail-patella syndrome	
Necrotizing enterocolitis	
Neurological disorder, Progressive	
Nonoxynol-9 spermicide, Early myoclonic	
encephalopathy syndrome and	(Oct 93) Feb
Norrie disease and cataplexy	
Obsessive-compulsive disorder	Jul Oct
Panic attacks?	
Parent, Single, with disabilities	
Parents, adoptive	
Parents with disabilities	(Nov/Dec 93)Feb
Parents with learning disability	Mar
Pen pal for sibling	
Personal attendant, College with	
Pfeiffer syndrome	Nov
Prader-Willi syndrome with normal DNA test	MayJul. Aug
PTO activities	
Puberty, Autism and	
Rasmussen syndrome	
Recreation, Therapeutic	
Rhizotomy	Mav Sep
Ring chromosome 22	
Ritalin, Autism and	
Robinow syndrome	
School bus, Riding the	Feb May 42
Scoliosis	
Seizures	
Seizures, Bleeding during	
Seizures, Uncontrollable	Feb
Semilobar holoprosencephaly	(Nov/Dec 93) Feb
Service dogs	Feb
Shaking, Severe	
Shoes, Wide	
Single parent with disabilities	
Skeletal anomalies	
Spastic paraparesis	Apr
Spina Bifida, Two children with	Aug Oct
Stepparenting	Nov
Strokes, Ischemic	Apr Jul
Teeth grinding	Jun Aug
Therapeutic recreation	
Transporting two non-ambulatory children.	
Trisony 4p/Monsomy 5p	~
Trisony 8, Partial	Sep
Trisomy 19Q	Sep Jul
	Jul
Twins, Identical, One with a disability	Jul Feb Oct Dec
'Iwins, Identical, One with a disability Umbilical cord sampling	Jul Feb Oct Dec May
Umbilical cord sampling	Jul Feb Oct Dec May
Umbilical cord sampling	Jul Feb Oct Dec May (Nov/Dec 93). Mar, Api Aug Nov
Umbilical cord sampling	Jul Feb Oct Dec May (Nov/Dec 93). Mar, Api Aug Nov
Umbilical cord sampling	JulFebOctDecMay(Nov/Dec 93). Mar, ApiAugNov
Umbilical cord sampling Undiagnosed Undiagnosed Undiagnosed Ventilator, Cart for Ventilator dependence	JulFebOctDecMay . (Nov/Dec 93). Mar, ApiNovSepMarMarMarAugNov
Umbilical cord sampling Undiagnosed Undiagnosed Undiagnosed Ventilator, Cart for Ventilator dependence	JulFebOctDecMay . (Nov/Dec 93). Mar, ApiNovSepMarMarMarAugNov
Umbilical cord sampling Undiagnosed Undiagnosed Undiagnosed Ventilator, Cart for Ventilator dependence Voice amplification equipment	JulFebOctDecMay .(Nov/Dec 93). Mar, AprNovSepMarAugNovOct
Umbilical cord sampling Undiagnosed Undiagnosed Undiagnosed Ventilator, Cart for Ventilator dependence. Voice amplification equipment Vomiting problem.	JulFebOctDecMay .(Nov/Dec 93). Mar, AprAugNovSepMarAugNovOctJunOct
Umbilical cord sampling Undiagnosed Undiagnosed Undiagnosed Ventilator, Cart for Ventilator dependence Voice amplification equipment	JulFebOctDecMay .(Nov/Dec 93). Mar, AprAugNovSepMarAugNovOctJunOctSepNov





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Circle #141 See our ad on page 112.

GMR Labs

1030 E El Camino Real, #308 Sunnwale, CA 94087 (408) 985-7200 (408) 243-3731 (fax) Circle #13

See our ad on page 54.

Gus Communications, Inc.

PO Box 4362 Blaine, WA 98231-4362 (604) 279-0110 (604) 279-8474 (fax)

Circle #36 See our ad on page 112.

IBM Special Needs Systems 1000 NW 51st St Boca Raton, FL 33432 (800) 426-4832 (407) 982-6059 (fax)

Circle #92 See our ad on page 104.

imaginart Communication Products

307 Arizona St Bisbee, AZ 85603 (800) 828-1376 (602) 432-5134 (fax) Circle #145

See our ad on page 90.

Jesana Ltd. -PO Box 17 Irvington, NY 10533 (800) 443-4728 (914) 591-4320 (fax) Circle #178 See our ad on page 97. **LC Technologies**

9455 Silver King Ct Fairfax, VA 22031 (703) 385-7133 (703) 385-7137 (fax) Circle #163

See our ad on page 96.

Passy-Muir, Inc. 4521 Campus Dr. Ste 273 Irvine, CA 92715 (714) 833-8255 (714) 833-8299 (fax)

Prentke Romich Company

1022 Hevi Rd Wooster, OH 44691 (800) 262-1933 (216) 263-4829 (fax) Circle #59

See our ad on page 52. Sentient Systems Technology Inc.

2100 Warburton St Pittsburgh, PA 15203-1942 (800) 344-1778 (412) 381-5241 (fax) Circle #161

See our ad on page 84.

Temasek Telephone, Inc. 21 Airport Blvd #G SoSan Francisco, CA 94080 (415) 875-6666 (415) 875-7608 (fax) Circle #121 See our ad on page 40.

Tiger Communication System, Inc.

155 E Broad St. Ste 325 Rochester, NY 14604 (800) 724-7301 (716) 454-3631 (fax) Circle #40

See our ad on page 116. WorkLink

2452 Armstrona St Livermore, CA 94550 (510) 606-3763 (510) 606-3769 (fax)

Bathroom Equipment

AccessAble Environments & Products

111 Cedar St New Rochelle, NY 10801 (800) 285-2525 (914) 632-1357 (fax)

Circle #103 See our ad on page 74.

Adaptive Design Shop

12847 Pt Pleasunt Dr Fairfax, VA 22033 (703) 631-1585 Circle #32

See our ad on page 111.

American Standard (Pressalit)

One Centennial Ave PO Box 6820 Piscataway, NJ 08855 (800) 524-9797 ext. 469 Circle #175

See our ad on page 45.

Barrier Free Lifts, Inc. PO Box 4163 Manassas, VA 22110 (703) 361-6531 (703) 361-7861 (fax)

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Clarke Health Care Products PIIP/ICM Blda 1003 International Dr Oakdale, PA 15071-9223

(412) 695-2122 (412) 695-2922 (fax)

Columbia Medical Mfg. Corp.

PO Box 633 Pacific Palisades, CA 90272 (800) 454-6612 (310) 305-1718 (fax) Circle #152

See our ads on pages 12 & 121.

H.D.I.S. Company, inc. 1215 Dielman Industrial Ct St. Louis, MO 63132 (800) 538-1036 (314) 997-0047 (fax) Circle #15

See our insert on pages 67-70.

Lubidet USA, Inc. 950 S Cherry St. 506 Denver, CO 80222 (800) 582-4338/(303) 757-3031 (303) 757-3868 (fax)

Circle #117 See our ad on page 122. **NCM Consumer Products** Division

PO Box 6070 San Jose, CA 95150 (800) 235-7054 (408) 277-6824 (fax)

Circle #68 See our ad on page 104.

Ortho-Kinetics, Inc.

W220 N 507 Springdale Rd Waukesha, WI 53187 (800) 558-7786

(414) 542-0625 (fax)

Tumble Forms 744 W Michigan Ave Jackson, MI 49203 (517) 789-3377 (517) 789-3333 (fax) Circle #27 See our ad on back cover.

Bedding

Hard Manufacturing Co., Inc.

230 Grider St Buffalo, NY 14215-3797 (800) USE-HARD/(716) 893-1800 (716) 896-2579 (fax)

Circle #44 See our ad on page 42.

Bicycles/Tricycles

Just Two Bikes, Inc. 4821 Washington Ave White Bear Lake, MN 55110 (800) 499-1548 (612) 426-1548 (fax)

Circle #140 See our ad on page 104. **Rock N'Roll Cycles**

PO Box 1558 Levelland, TX 79336 (800) 654-9664 (806) 894-9646 (fax) Circle #171

See our ad on page 41.

Step'n Go Cycles PO Box 180, Cedar Beach Rd Charlotte, VT 05445 (800) 648-7335 (802) 425-2264, ext 254 (802) 425-3007 (fax)

Circle #125 See our ad on page 113.

Triaid PO Box 1364 Cumberland, MD 21502 (800) 306-6777/(301) 759-3525 (301) 759-3525 (fax) Circle #46

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eSpecials (Down Syndrome/PW)

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i-2 Kids Clothes

100 Springdale Rd A-3, Ste 164 Cherry Hill, NJ 08003 (609) 770-8474 (609) 427-9560 (fax)

Kotton & Koala

PO Box 178 Fort Jones, CA 96032 (916) 468-5475 (916) 468-5492 (fax)

Circle #18

See our ad on page 96.

M.J. Markell Shoe Co.

504 Saw Mill River Rd Yonkers, NY 10701 (914) 963-2258 (914) 963-9293 (fax)

Circle #1

See our ad on page 56.

Moonbeams-Carol Nesper **Studios**

2026 Murray Hill Rd Cleveland, OH 44106 (216) 721-4100

Circle #61

See our ad on page 39.

Special Clothes

PO Box 4220 Alexandria, VA 22303 (703) 683-7343 (703) 549-2640 (fax)

Wheelin' Wear (Children's Gloves)

PO Box 545 Cobourg, ON Canada K9A 4L3 (800) 488-2638 (905) 373-4941 (fax)

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See our ad on page 97.

Don Johnston Incorporated 1000 N Rand Rd, Bldg 115 Wauconda, IL 60048 (800) 999-4660/(708) 526-2682 (708) 526-4177 (fax)

Circle #142

See our ad on page 112.

EKEG Electronics Co. Ltd.

PO Box 46199, Station D. Vancouver, BC Canada V6J 5G5 (604) 273-4358 (604) 273-1148 (fax)

IBM Special Needs Systems

1000 NW 51st St Boca Raton, FL 33432 (800) 426-4832 (407) 982-6059 (fax)

Circle #92

See our ad on page 104.

In Touch Systems

11 Westview Rd Spring Valley, NY 10977 (800) 332-MAGIC

Circle #122

See our ad on page 56.

IntelliTools, Inc.

5221 Central Ave. #205 Richmond, CA 94804 (800) 879-6687/(510) 528-0670 (510) 528-2225 (fax)

Circle #42

See our ad on page 74.

Key Concepts

PO Box 21066 Charlotte, NC 28277 (800) 293-5090

Circle #50

See our ad on page 88.

RJ Cooper & Associates

24843 Del Prado, #283 Dana Point, CA 92629 (800) RJCOOPER (714) 240-9785 (fax) Circle #81

See our ad on page 79. Synergy

68 Hale Rd Walpole, MA 02032 (508) 668-7424 (508) 663-4134 (fax)

WorkLink

2452 Armstrong St Livermore, CA 94550 (510) 606-3763 (510) 606-3769 (fax)

Driving Aids

Adaptive Driving Systems

21050 Superior St Chatsworth, CA 91311 (818) 998-1026 (818) 882-0812 (fax)

Crow River Industries

14800 28th Ave N Minneapolis, MN 55447 (800) 488-7688 (612) 557-8310 (fax) Circle #120

See our ad on page 92.

GM Mobility Assistance Center

PO Box 9011 Detroit, MI 48202 (800) 323-9935 (800) 833-9935 (TTY) (313) 974-4383 (fax)

Circle #94

See our ad on page 73.

Monmouth Vans, Access & Mobility

5105 Rte 33/34 Farmingdale, NJ 07727 (800) 221-0034 (908) 919-0256 (fax)

Ricon Corporation

12450 Montague St Pacoima, CA 91331 (818) 899-7588 (818) 890-3354 (fax)

Circle #86

See our ad on page 53.

Educational Material

Attainment Company, Inc.

PO Box 930160 Verona, WI 53593-0160 (800) 327-4269 (800) 942-3865 (fax)

Bo Peep Productions Videotapes

PO Box 982 Eureka, MT 59917 (800) 532-0420 (406) 889-3225 (fax)

Don Johnston Incorporated

1000 N Rand Rd, Bldg 115 Wauconda, IL 60048 (800) 999-4660/(708) 526-2682 (708) 526-4177 (fax)

Circle #143

See our ad on page 112.

Gemma B. Publishing, Inc.

Box #713-740 Corvdon Ave Winnipeg, MB Canada R3M OY1 (204) 452-7566 (204) 475-9903 (fax)

Mind Play

160 W Ft Lowell Tucson, AZ 85705 (800) 221-7911 (602) 888-7904 (fax)

River Tank Systems

PO Box 445 Exeter, RI 02822 (800) 808-8822 (401) 294-9510 (fax) Circle #5

Voicing!

3857 Birch, Ste 194 Newport Beach, CA 92660 (714) 833-2710 (714) 833-1005 (fax)

See our ad on page 55.

Environmental Controls

Jesana Ltd.

PO Box 17 Irvington, NY 10533 (800) 443-4728 (914) 591-4320 (fax) Circle #179 See our ad on page 97.

Finance/Estate Planning/insurance

Abilities Plus Program

Special Auto & Home Insurance PO Box 5198 Lutherville, MD 21094-9719 (800) 222-2788, Dept Q Circle #137

See our ad on page 80.

Assoc for Special Kids (ASK) 107 W Hill St Baltimore, MD 21230 (800) 832-0467/(410) 727-2118 (410) 727-3266 (fax)

Estate Planning (EPPD)

1200 Corporate Dr, Ste 330 Birmingham, AL 35242 (800) 448-1071 (800) 880-9327 (fax) Circle #31

See our ad on page 95. **Food & Nutrition**

Medical Innovations Corporation

12050 Lone Peak Pkwy Draper, UT 84020 (801) 572-6800 (801) 572-6869 (fax)

Furniture

Columbia Medical Mfg. Corp.

PO Box 633 Pacific Palisades, CA 90272 (800) 454-6612 (310) 305-1718 (fax) Circle #155

See our ads on pages 12 & 121.

Equipment Shop PO Box 33 Bedford, MA 01730 (617) 275-7681 (617) 275-4094 (fax) Circle #123

Headgear

Ortho-Kinetics, Inc.

W220 N 507 Springdale Rd Waukesha, WI 53187 (800) 558-7766 (414) 542-0625 (fax)

See our ad on page 88.

Plum Enterprises, Inc.

9 Clyston Cir/PO Box 283 Worcester, PA 19490 (800) 321-PLUM (215) 584-4151 (fax) Circle #12

See our ad on page 3.

Hearing Aids/Equipment

Oticon, Inc.

29 Schoolhouse Rd Somerset, NJ 08875 (800) 227-3921 (908) 560-0029 (fax)

Hobbles & Toys

The Dragonfiv Toy Company

291 Yale Ave Winnipeg MB Canada R3M 0L4 (204) 453-2222 (204) 453-2320 (fax)

InvoTek Corporation

700 W 20th St, ENRC Favetteville, AR 72701 (800) 576-6661 (501) 575-7446

River Tank Systems

PO Box 445 Exeter, RI 02822 (800) 808-8822 (401) 294-9510 (fax)

Circle #5 See our ad on page 55.

Rock N'Roll Cycles

PO Box 1558 Levelland, TX 79336 (800) 654-9664 (806) 894-9646 (fax) Circle #172

See our ad on page 41.

Sony Electronics, Inc. 2 Van Riper Rd Montvale, NJ 07645-0406 (201) 476-8160 (201) 476-8071 (fax)

Circle #104 See our ad on page 100.

Switch Kids, Inc. 8507 Rupp Farm Dr West Chester, 0H 45069 (513) 860-5475 (513) 860-5475 (fax)

TFH (USA)-**Fun and Achievement**

4537 Gibsonia Rd Gibsonia, PA 15044 (412) 444-6400 (412) 444-6411 (fax) **Toys for Special Children**

385 Warburton Ave Hastings-on-Hudson, NY 10706 (800) 832-8697 Circle #160

See our ad on page 48.

Voicina!

3857 Birch, Ste 194 Newport Beach, CA 92660 (714) 833-2710 (714) 833-1005 (fax)

Home Adaptation/Design

AccessAble Environments & Product

111 Cedar St New Rochelle, NY 10801 (800) 285-2525 (914) 632-1357 (fax) Circle #103

See our ad on page 74.

Homecare Products, Inc. 15824 SE 296th St Kent, WA 98042 (800) 451-1903 (206) 630-8196 (fax) Circle #101

See our ad on page 134. **River Tank Systems**

PO Box 445 Exeter, RI 02822 (800) 808-8822 (401) 294-9510 (fax) Circle #5 See our ad on page 55.

Home Health Care Services

Kennedy Krieger Institute 707 N Broadway Baltimore, MD 21205 (800) 873-3377/(410) 550-9400 (410) 550-8217 (fax)

Circle #70 See our ad on page 98.

Olsten Kimberly QualityCare 175 Broadhollow Rd Melville, NY 11747

(800) 66-NURSE (508) 383-7514 (fax)

Circle #165 See our ad on page 4.

Vail Products, Inc. (Bed Systems)

235 First St Toledo, OH 43605 (800) 235-8245 (419) 698-1174 (fax) Circle #35

See our ad on page 40.

Incontinence Products

All the Best-(Reusables Only) 6846 19th Ave NE

Seattle, WA 98115 (206) 523-1725

ARC Home Health Care Products

RR #4 Box 161 Oneonta, NY 13820 (800) 278-8595 (607) 433-6745 (fax) Circle #75

See our ad on page 112.

Direct Delivery-Promise Products

PO Box 79603 Houston, TX 77279-9603 (800) 659-8037 (713) 869-5586 (fax)

Express Medical Supply

PO Box 1164 Fenton, MO 63026 (800) 633-2139/(314) 349-8448 (314) 349-8469 (fax) Circle #157

See our ad on page 74.

G. Hirsch & Co. Inc. 1815 Rollins Rd Burlingame, CA 94010 (415) 692-8770 (415) 692-1874 (fax)

H.D.I.S. Company, Inc. 1215 Dielman Industrial Ct St. Louis, MO 63132 (800) 538-1036

(314) 997-0047 (fax) Circle #14

See our insert on pages 67-70. Humanicare International, Inc.

1471 Jersey Ave North Brunswick, NJ 08902 (800) 631-5270 (908) 214-0666 (fax)

Circle #90 See our ad on page 46.

Kimberly-Clark Corporation PO Box 2020 Neenah, WI 54957-2020 (800) 544-1847

See our ad on page 14.

Mentor Urology 5425 Hollister Ave Santa Barbara, CA 93111

(800) 328-3863 (805) 967-7108 (fax)

Principle Business Enterprises

Pine Lake Industrial Pk Dunbridge, OH 43414 (419) 352-1551 (419) 352-8340 (fax) Circle #89

Special Products

212 N Market, Ste 315 Wichita, KS 67202-2016 (800) 553-3492 Circle #167

See our ad on page 89.

See our ad on page 96.

TAGA

PO Box 313 Somerset, NJ 08873

TMI (Technomarketing, Inc.)

307 Bacon Rd Rougemont, NC 27572 (919) 477-1387 (919) 477-2294 (fax)

Circle #19

See our ad on page 43. **Woodbury Products**

4410 Austin Blvd, Dept 250 Island Park, NY 11558 (800) 777-1111 (516) 431-6793 (fax)

Circle #72 See our ad on page 80.

Medical Equipment **Dealers**

MED Certified Repair Centers 3223 S Loop 289, Ste 600 Lubbock, TX 79423 (800) 477-6272 Call for location near you.

Circle #93 See our ad on inside back cover.

Passy-Muir, Inc.

4521 Campus Dr. Suite 273 Irvine, CA 92715 (714) 833-8255 (714) 833-8299 (fax)

Vail Products, Inc. (Bed Systems)

235 First St Toledo, OH 43605 (800) 235-8245 (419) 698-1174 (fax) Circle #34

See our ad on page 40.

Personal Care/Dental

NR Labs, Inc. 900 E Franklin St Centerville, OH 45459-5620 (513) 433-9570 Circle #139

See our ad on page 40.



ERICI28 •

Oralgiene USA, Inc.

421 N Rodeo Dr. Ste 15114 Beverly Hills, CA 90210 (800) 933-ORAL (6725)

Circle #184

See our ad on page 13.

Publishers/Catalogs

Alexander Graham Bell Assoc f/t Deaf

3417 Volta PI, NW Washington, DC 20007 (202) 337-5220 (202) 337-8314 (fax)

Attainment Company, Inc.

P0 Box 930160 Verona, WI 53593-0160 (800) 327-4269 (800) 942-3865 (fax)

Charles C. Thomas Publishing Co.

2600 South St Springfield, IL 62794 (217) 789-8980 (217) 789-9130 (fax)

Circle #25

See our ad on page 66.

Communication Skill Bullders

3830 E Bellevue Tucson, AZ 85716 (800) 866-4446 (602) 325-0306 (fax)

Don Johnston, Inc.

1000 N Rand Rd. Bldg 115 Wauconda, IL 60048 (800) 999-4660/(708) 526-2682 (708) 526-4177 (fax)

Circle #144 See our ad on page 112.

Edmark Corp.

PO Box 97021 Redmond, WA 98073-9721 (800) 362-2890 (206) 556-8430 (fax)

Circle #109

See our ad on page 10.

Express Medical Supply

PO Box 1164 Fenton, MO 63026 (800) 633-2139/(314) 349-8448 (314) 349-8469 (fax)

Circle #158 See our ad on page 74.

Interax Training, Inc.

PO Box 473106 Garland, TX 75047-3106 (800) 242-5583

Jason & Nordic Publishers

PO Box 441 Hollidaysburg, PA 16648 (814) 696-2920 (814) 696-4250 (fax)

NCM Consumer Products Division

P0 Box 6070 San Jose, CA 95150 (800) 235-7054 (408) 277-6824 (fax)

Circle #68

See our ad on page 104.

The Prader-Willi Forum

40 Holly Ln Roslyn Heights, NY 11577 (800) 358-0682 (516) 484-7154 (fax)

Circle #43

See our ad on page 71.

Special Needs Project

3463 State St Santa Barbara, CA 93105 (800) 333-6867

Sportime Abilitations

One Sportime Wy Atlanta, GA 30340 (800) 850-8602 (800) 845-1535 (fax)

Circle #22

See our ad on page 10.

Tumble Forms

744 W Michigan Ave Jackson, MI 49203 (517) 789-3377 (517) 789-3333 (fax)

Circle #29

See our ad on back cover.

Voicina!

3857 Birch, Ste 194 Newport Beach, CA 92660 (714) 833-2710 (714) 833-1005 (fax)

Woodbine House

6510 Bells Mill Rd Bethesda, MD 20817 (800) 843-7323

Ramps/Lifts

Adaptive Driving Systems

21050 Superior St Chatsworth, CA 91311 (818) 998-1026 (818) 882-0812 (fax)

Aquatic Access, Inc. 411 Dorsey Wy

Louisville, KY 40223 (502) 425-5817 (502) 425-9607 (fax)

Barrier Free Lifts, Inc.

PO Box 4163 Manassas, VA 22110 (703) 361-6531 (703) 361-7861 (fax) Circle #39

See our ad on page 44.

The Braun Corporation

1014 S Monticello St Winamac, IN 46996 (800) THE-LIFT (219) 946-4670 (fax)

Circle #112

See our ads on pages 9 &11.

Bruno Independent Living Aids

1780 Executive Dr/PO Box 84 Oconomowoc, WI 53066 (800) 882-8133 (414) 567-4341 (fax) Circle #7

See our ad on page 76.

Crow River Industries

14800 28th Ave N Minneapolis, MN 55447 (800) 488-7688 (612) 557-8310 (fax)

Circle #119

See our ad on page 92.

GM Mobility Assistance Center

PO Box 9011 Detroit, MI 48202 (800) 323-9935 (800) 833-9935 (TTY) (313) 974-4383 (fax)

Circle #95

See our ad on page 73.

Homecare Products, Inc.

15824 SE 296th St Kent, WA 98042 (800) 451-1903 (206) 630-8196 (fax) Circle #101

See our ad on page 134.

Monmouth Vans, Access & Mobility

5105 Rte 33/34 Farmingdale, NJ 07727 (800) 221-0034 (908) 919-0256 (fax)

Ricon Corporation

12450 Montague St Pacoima, CA 91331 (818) 899-7588 (818) 890-3354 (fax) Circle #85 See our ad on page 53.

Rehabilitation Centers/Hospitals

Children's Seashore House

3405 Civic Center Blvd Philadelphia, PA 19104 (800) 678-3733/(215) 895-3600

Children's Specialized Hospital

150 New Providence Rd Mountainside, NJ 07092-2590 (908) 233-3720 (908) 233-4176 (fax) Circle #11

See our ad on page 51.

Cumberland Hospital

9407 Cumberland Rd New Kent, VA 23124 (800) 368-3472 Circle #74

See our ad on page 99.

Kennedy Krieger Institute

707 N Broadway Baltimore, MD 21205 (800) 873-3377/(410) 550-9400 (410) 550-8217 (fax)

Circle #70

See our ad on page 98.

Olsten Kimberly QualityCare

175 Broadhollow Rd Melville, NY 11747 (800) 66-NURSE (508) 383-7514 (fax) Circle #165

See our ad on page 4.

The Children's Hospital at St. Joseph's

703 Main St Paterson, NJ 07503 (201) 977-2500 (201) 684-5025 (fax) Circle #17

See our ad on page 117.

Voorhees Pediatric Facility 1304 Laurel Oak Rd

Voorhees, NJ 08043 (609) 346-3300 (609) 435-4223 (fax)

Circle #108

See our ad on page 56.

Repair Services-Medical **Equipment Dealers**

MED Certified Repair Centers 3223 S Loop 289, Ste 600 Lubbock, TX 79423 (800) 477-6272

Call for location near you. Circle #93

See our ad on inside ba: k cover.

Schools/Camps/ Residences

Annandale at Suwanee, inc.

3500 Annandale Ln/Box 7 Suwanee, GA 30174 (404) 945-8381

Berkshire Meadows

249 N Plain Rd Housatonic, MA 01236 (413) 528-2523

Circle #10 See our ad on page 107.

Camp Huntington PO Box 3789

Poughkeepsie, NY 12603 (914) 687-7840

Camphill Special School

1784 Fairview Rd Glenmoore, PA 19343 (610) 469-9236 (610) 469-9758 (fax)

Children's Care Hospital & School

2501 W 26th St Sioux Falls, SD 57105 (800) 584-9294/(605) 336-1840

CIB/Oak Hill 120 Holcomb St

Hartford, CT 06112 (203) 242-2274 (203) 242-3103 (fax)

Crotched Mountain

1 Verney Dr Greenfield, NH 03047 (603) 547-3311

Circle #73 See our ad on page 75.

Crystal Springs School

38 Narrows Rd, Box 372 Assonet, MA 02702 (508) 644-5537 (508) 644-3101, ext 372 (fax)

Circle #124 See our ad on page 72.

Dr. Gertrude A. Barber Center

136 East Ave Erie. PA 16507 (814) 453-7661 (814) 454-2771 (fax)

Elwyn, Inc.

111 Elwyn Rd Elwyn, PA 19063-4699 (800) 345-8111/(610) 891-2000

Circle #79

See our ad on page 82.

Evergreen Center 345 Fortune Blvd Milford, MA 01757 (508) 478-5597 (508) 634-3251 (fax)

Circle #106 See our ad on page 90.

Heartspring

2400 Jardine Dr Wichita, KS 67219 (800) 835-1043 (316) 262-0170 (fax)

Circle #3

See our ad on page 54.

HMS School for Children with CP

4400 Baltimore Ave Philadelphia, PA 19104 (215) 222-2566

Circle #77 See our ad on page 51. **Keystone City Residence** & Camp

c/o 406 N Wash. Ave Scranton, PA 18503 (800) 232-1753 (717) 342-3461 (fax)

Circle #48 See our ad on page 71.

LARC School, Inc. Creek Rd & Park Dr Beilmawr, NJ 08031

(609) 933-3725 (609) 933-3158 (fax)

League School of Boston 225 Nevada St

Newtonville, MA 02160 (617) 964-3260

Circle #24

See our ad on page 88.

Martha Lloyd Community Services

190 W Main St Troy, PA 16947 (717) 297-2185

Circle #78 See our ad on page 105.

Meeting Street Center

667 Waterman Ave East Providence, RI 02914 (401) 438-9500 (401) 438-3690 (TDD) (401) 438-3760 (fax)

Circle #83

See our ad on page 44.

Melmark

Wayland Rd Berwyn, PA 19312 (610) 353-1726 (610) 353-8528 (fax)

Circle #69 See our ad on page 113.

Natl Christian Resource Ctr on MR

700 Hoffman Dr Watertown, WI 53094 (800) 369-INFO

Circle #84

See our ad on page 132.

New England Villages

664 EP School St Pembroke, MA 02359 (617) 293-5461

Circle #21 See our ad on page 39.

St. Coletta's of Mass. 400 Washington St Hanover, MA 02339 (617) 826-6371 (617) 826-6474 (fax) Circle #162

See our ad on page 104.

Stewart Home School

Box 20 Frankfort, KY 40601 (502) 875-4664

Circle #4

See our ad on page 56.

The Devereux Foundation 19 S Waterloo Rd, PO Box 400 Devon, PA 19333 (800) 345-1292, ext 3045 (610) 971-4600 (fax)

Circle #107

See our ad on page 91.

The Guided Tour's Camp Lee Mar

7900 Old York Rd. Ste 114-B Elkins Park, PA 19027-2339 (215) 782-1370

(215) 635-2637 (fax) Circle #136

See our ad on page 116.

The Learning Center 411 Waverly Oaks Rd

Waltham, MA 02154 (617) 893-6000

The New England Center for Autism

33 Turnpike Rd Southboro, MA 01772 (508) 481-1015

Circle #76 See our ad on page 46.

Willow River Farms

PO Box 450 San Felipe, TX 77473 (409) 885-4121 Circle #91

See our ad on page 80.

Scooters

Bruno Independent Living Aids

1780 Executive Dr/PO Box 84 Oconomowoc, WI 53066 (800) 882-8133 (414) 567-4341 (fax) Circle #8

See our ad on page 76.

Ortho-Kinetics, Inc. W220 N 507 Springdale Rd Waukesha, WI 53187 (800) 558-7786 (414) 542-0625 (fax)

Seating & Positioning

Adaptive Design Labs

15 Standish Ave West Orange, NJ 07052 (201) 736-4443 (201) 736-3673 (fax) Circle #2

See our ad on page 98.

Bruno Independent Living Aids 1780 Executive Dr/PO Box 84 Oconomowoc, Wi 53066 (800) 882-8133 (414) 567-4341 (fax) Circle #9

See our ad on page 76. Child Quest, Inc. Seatkeeper PO Box 18595

Austin, TX 78760 (800) 732-8533 (512) 385-6178 (fax)

Circle #38 See our ad on page 96.

Columbia Medicai Mfg. Corp.

PO Box 633 Pacific Palisades, CA 90272 (800) 454-6612 (310) 305-1718 (fax)

Circle #153

See our ads on pages 12 & 121.

Consumer Care Products, Inc.

PO Box 684 Sheboygan, WI 53082-0684 (414) 459-8353

(414) 459-9070 (fax) Circle #138

See our ad on page 90.

Convaid Products, Inc. PO Box 2458

Palos Verdes, CA 90275 (800) 552-1020/(310) 539-6814 (310) 539-3670 (fax)

Circle #127 See our ad on page 81.

Express Medical Supply

PO Box 1164 Fenton, MO 63026 (800) 633-2139/(314) 349-8448 (314) 349-8469 (fax)

Circle #159

See our ad on page 74. Freedom Designs, Inc.

2241 Madera Rd Simi Valley, CA 93065 (800) 331-8551/(805) 582-0077 (805) 582-1509 (fax)

Circle #169 See our ad on page 124.

James Leckey Design, inc.

360 Merrimack St Riverwalk Bldg 5 Lawrence, MA 01843 (508) 691-5220 (508) 691-5230 (fax)

Circle #57 See our ad on page 39.



Jav Madichi Ltd.

PO Box 18656 Boulder, CO 80202 (800) 648-8282/(303) 442-5529 (303) 442-3855 (fax)

Circle #148

See our ad on page 108.

Jesana Ltd.

PO Box 17 Irvington, NY 10533 (800) 443-4728 (914) 591-4320 (fax)

Circle #180

See our ad on page 97.

Kennedy Krieger Institute

707 N Broadway Baltimore, MD 21205 (800) 873-3377/(410) 550-9400 (410) 550-8217 (fax)

Circle #71

See our ad on page 98.

Meeting Street Center

667 Waterman Ave East Providence, RI 02914 (401) 438-9500 (401) 438-3690 (TDD)

(401) 438-3760 (fax)

Circle #83 See our ad on page 44.

Mulholland Positioning Systems

PO Box 391, 215 N 12th St Santa Paula, CA 93061 (800) 543-4769 (805) 933-1082 (fax)

Circle #64

Ortho-Kinetics, Inc.

W220 N 507 Springdale Rd Waukesha, Wi 53187 (800) 558-7786 (414) 542-0625 (fax)

Rifton

PO Box 901 Rifton, NY 12471-0901 (800) 374-3866 (914) 658-8065 (fax)

Circle #41

See our ad on page 52.

Snug Seat

1081 Independence Point Pkwy Matthews, NC 28106 (704) 847-0772 (704) 847-9577 (fax) Circle #52

See our ad on page 57.

Special Designs, Inc.

PO Box 130 Gillette, NJ 07933 (908) 464-8825 (908) 464-8251 (fax) Circle #130

See our ad on page 98.

Taylor Made Healthcare

10 W 9th Ave Gloversville, NY 12078 (800) 258-0942 (518) 773-9375 (fax)

Circle #134

See our ad on page 72.

Tumble Forms

744 W Michigan Ave Jackson, MI 49203 (517) 789-3377 (517) 789-3333 (fax) Circle #28

See our ad on back cover.

Software

Articulate Sys. Voice Recognition

600 W Cummings Pk, Ste 4500 Woburn, MA 01801 (800) 443-7077 (617) 935-0490 (fax)

Edmark Corp.

PO Box 97021 Redmond, WA 98073-9721 (800) 362-2890 (206) 556-8430 (fax) Circle #109

See our ad on page 10.

KidTECH/SoftTouch

3204 Perry PI Bakersfield, CA 93306 (805) 873-8744 (805) 871-9679 (fax)

Circle #177

See our ad on page 42.

Laureate Learning Systems, Inc.

110 E Spring St Winooski, VT 05404 (800) 562-6801/(802) 655-4755 (802) 655-4757 (fax)

Circle #45

See our ad on page 52.

Marblesoft

12301 Central Ave NE. Ste 205 Blaine, MN 55434 (612) 755-1402 (612) 755-1402 (fax, call first) Circle #16

See our ad on page 42.

RJ Cooper & Associates

24843 Del Prado, #283 Dana Point, CA 92629 (800) RJCOOPER (714) 240-9785 (fax)

Circle #82

See our ad on page 79.

Sports/Recreation/Family

Aquatic Therapy

1903 E B Ave Plainwell, MI 49080 (616) 349-9049 (616) 349-9049 (fax) Circle #118

See our ad on page 42.

Bail Dynamics Int'l, Inc.

1616 Glenarm Pl., Ste #1900 Denver, CO 80202 (800) 752-2255 (303) 893-0524 (fax)

Circle #111

See our ad on page 113.

Flaghouse, inc.

150 N MacQuesten Pkwy Mt. Vemon, NY 10550 (800) 793-7900/(914) 699-1900 (800) 793-7922 (fax)

Circle #132

See our ad on page 88.

Jay Medical Ltd.

PO Box 18656 Boulder, CO 80202 (800) 648-8282/(303) 442-5529 (303) 442-3855 (fax)

Circle #149

See our ad on page 108.

Jesana Ltd.

PO Box 17 Irvington, NY 10533 (800) 443-4728 (914) 591-4320 (fax)

Circle #181

See our ad on page 97.

River Tank Systems

PO Box 445 Exeter RI 02822 (800) 808-8822 (401) 294-9510 (fax) Circle #5

See our ad on page 55.

Rock N'Roll Cycles

PO Box 1558 Levelland, TX 79336 (800) 654-9664 (806) 894-9646 (fax)

Circle #173

See our ad on page 41.

Roleez Wheel System

5711A Sellger Dr/Dept E Norfolk, VA 23502 (800) 369-1390/(804) 461-1122 (804) 461-0383 (fax)

Circle #47

See our ad on page 112.

Top End by Action

4501 63rd Cir N Pinellas Park, FL 34665

(800) 532-8677/(813) 522-8677 (813) 522-1007 (fax)

Standing Equipment

James Leckey Design, Iric.

360 Merrimack St Riverwalk Bldg 5 Lawrence, MA 01843 (508) 691-5220 (508) 691-5230 (fax) Circle #58

See our ad on page 39.

Mulholiand Positioning Systems

PO Box 391, 215 N 12th St Santa Paula, CA 93061 (800) 543-4769 (805) 933-1082 (fax) Circle #65

Ortho-Kinetics, Inc.

W220 N 507 Springdale Rd Waukesha, WI 53187 (800) 558-7786 (414) 542-0625 (fax)

Snug Seat

1081 Independence Point Pkwy Matthews, NC 28106 (704) 847-0772 (704) 847-9577 (fax)

Circle #55 See our ad on page 57.

Strollers

Coiumbia Medical Mfg. Corp.

PO Box 633 Pacific Palisades, CA 90272 (800) 454-6612 (310) 305-1718 (fax)

Circle #154

See our ads on pages 12 & 121.

Convaid Products, inc.

PO Box 2458

Palos Verdes, CA 90275 (800) 552-1020/(310) 539-6814 (310) 539-3670 (fax)

Circle #128

See our ad on page 81.

Jesana Ltd.

PO Box 17 Irvington, NY 10533 (800) 443-4728 (914) 591-4320 (fax) Circle #182

See our ad on page 97.

Kid-Kart

732 Cruiser Ln Beigrade, MT 59714 (800) 388-5278 (406) 388-1081 (fax)

Circle #99

See our ad on page 12.

PO Box 391, 215 N 12th St Santa Paula, CA 93061 (800) 543-4769 (805) 933-1082 (fax)

Circle #66

Racing Strollers, Inc/ Baby Jogger PO Box 2189 Yakima, WA 98907-2189 (800) 241-1848

(509) 453-7732 (fax) Circle #63 See our ad on page 96.

Snug Seat 1081 Independence Point Pkwy Matthews, NC 28106 (704) 847-0772 (704) 847-9577 (fax)

Circle #54 See our ad on page 57.

Stroller-Pack
PO Box 20707
Juneau, AK 99802
(800) 487-9652/(907) 463-4843
(907) 463-4889 (fax)
Circle #164
See our ad on page 90.

Tumble Forms744 W Michigan Ave
Jackson, Mi 49203
(517) 789-3377
(517) 789-3333 (fax)

Circle #30 See our ad on back cover.

Telephone Equipment

InvoTek Corporation 700 W 20th St, ENRC Fayetteville, AR 72701 (800) 576-6661 (501) 575-7446

Ultratec, Inc. 450 Science Dr Madison, WI 53711 (800) 482-2424 (V/TTY) (608) 238-3008 (fax)

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The Guided Tour— Adult Travel 7900 Old York Rd, Ste 114-B Elkins Park, PA 19027-2339 (215) 782-1370 (215) 635-2637 (fax)

Vans

The Braun Corporation
1014 S Monticello St
Winamac, IN 46996
(800) THE-LIFT
(219) 946-4670 (fax)
Circle #114
See our ads on pages 9 & 11.

Chrysier Automobility Pregram

PO Box 3124 Bloomfield Hills, MI 48302-3124 (800) 225-9877

Circle #146 See our ad on page 47.

Ford Mobility Motoring Program

PO Box 529 Bloomfield Hills, MI 48303-9857 (800) 952-2248 (810) 621-3082 (fax)

Circle #135 See our ad on inside front cover.

GM Mobility Assistance Center

PO Box 9011 Detroit, MI 48202 (800) 323-9935 (800) 833-9935 (TTY) (313) 974-4383 (fax) Circle #96

See our ad on page 73.

Ricon Corporation 12450 Montague St Pacoima, CA 91331 (818) 899-7588 (818) 890-3354 (fax) Circle #87

Circle #87 See our ad on page 53.

Vantage Mini Vans 5214 S 30th St Phoenix, AZ 85040 (800) 348-8267 (602) 243-9843 (fax) Circle #102

See our ad on page 58. Van Conversions

Adaptive Driving Systems 3534 Empleo St, Ste B San Luis Obispo, CA 93401 (805) 549-7996 (818) 882-0812 (fax)

Arcola Mobility
51 Karo Rd
Carlstadt, NJ 07072
(800) ARCOLA-1/(201) 507-8500

The Braun Corporation 1014 S Monticello St Winamac, IN 46996 (800) THE-LIFT (219) 946-4670 (fax)

Circle #115 See our ads on pages 9 & 11.

Drive-Master, Inc. 9 Spielman Rd Fairfield, NJ 07004 (201) 808-9709 **Forward Motions**

214 Valley St Dayton, OH 45404 (513) 222-5001

GM Mobility Assistance Center

PO Box 9011
Detroit, MI 48202
(800) 323-9935
(800) 833-9935 (TTY)
(313) 974-4383 (fax)
Circle #97
See our ad on page 73.

Handicap Vehicle Specialists, Inc. 3306 E Washington, #

3306 E Washington, #106 Phoenix, AZ 85034-1624 (602) 275-3325 (602) 275-1536 (fax)

Independent Mobility Systems

4100 W Piedras Farmington, NM 87401 (800) IMS VANS (505) 326-4846 (fax)

Lift Aids, Inc. 2381 Pecan Ct Fort Worth, TX 76117 (817) 429-7141 (metro) (817) 834-3881 (817) 831-7842 (fax)

Monmouth Vans, Access & Mobility

5105 Rte 33/34 Farmingdale, NJ 07727 (800) 221-0034

New Era Transportation 810 Moe Dr Akron, OH 44310 (800) 638-8267/(216) 633-1118 (216) 633-0330 (fax)

Ricon Corporation 12450 Montague St Pacoima, CA 91331 (818) 899-7588 (818) 890-3354 (fax) Circle #88

See our ad on page 53.

Vantage Mini Vans

5214 S 30th St Phoenix, AZ 85040 (800) 348-8267 (602) 243-9843 (fax) Circle #102

Circle #102 See our ad on page 58.

Van Rentals

Wheelers, Accessible Van Rentals

6614 W Sweetwater Glendale, AZ 85304 (800) 456-1371 (602) 878-0501 (fax) Wheelchair Getaways, Inc.

PO Box 605 Versailles, KY 40383 (800) 642-2042 (606) 873-8039 (fax)

Walking Alds

Jesana Ltd. PO Box 17 Irvington, NY 10503 (800) 443-4728 (914) 591-4320 (fax)

Circle #183 See our ad on page 97.

Wheelchairs, Manual

Convaid Products, Inc. PO Box 2458 Palos Verdes, CA 90275 (800) 552-1020/(310) 539-6814 (310) 539-3670 (fax)

Circle #129 See our ad on page 81.

Freedom Designs, Inc. 2241 Madera Rd Simi Valley, CA 93065 (800) 331-8551/(805) 582-0077 (805) 582-1509 (fax) Circle #170

See our ad on page 124.

Kid-Kart 732 Cruiser Ln Belgrade, MT 59714 (800) 388-5278 (406) 388-1081 (fax)

Circle #100 See our ad on page 12.

MED Certified Repair Centers 3223 S Loop 289, Ste 600 Lubbock, TX 79423 (800) 477-6272 Call for location near you. Circle #93

Circle #93
See our ad on inside back
cover.
Mulholland Positioning

SystemsPO Box 391, 215 N 12th St
Santa Paula, CA 93061
(800) 543-4769
(805) 933-1082 (fax)

Circle #67

Ortho-Kinetics, Inc. W220 N 507 Springdale Rd Waukesha, WI 53187 (800) 558-7786 (414) 542-0625 (fax)

Rock N'Roll Cycles
PO Box 1558
Levelland, TX 79336
(800) 654-9664
(806) 894-9646 (fax)
Circle #174

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Snug Seat

1081 Independence Point Pkwy Matthews, NC 28106 (704) 847-0772 (704) 847-9577 (fax)

Circle #53

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TMI (Technomarketing, inc.)

307 Bacon Rd Rougemont, NC 27572 (919) 477-1387 (919) 477-2294 (fax)

Circle #20 See our ad on page 39.

Top End by Action

4501 63rd Cir N Pinellas Park, FL 34665 (800) 532-8677/(813) 522-8677 (813) 522-1007 (fax)

Wheelchairs, Powered

The Braun Corporation

1014 S Monticello St Winamac, IN 46996 (800) THE-LIFT (219) 946-4670 (fax) Circle #116

See our ads on pages 9 & 11.

innovative Products, Inc.

830 S 48th St Grand Forks, ND 58201 (800) 950-5185/(701) 772-5185 (701) 772-5284 (fax)

Circle #110

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MED Certified Repair Centers

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Circle #93

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Other

Assoc of Birth Defect Children

827 irma Ave Orlando, FL 32803 (800) 313-ABDC Circle #62

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Bustop Alert

254 Charlevoix Grosse Pointe Farms, MI 48236 (313) 885-8961 (313) 885-7075 (fax)

Circle #60

See our ad on page 82.

Diestco Manufacturing

PO Box 6504 Chico, CA 95927 (800) 795-2392 (916) 893-2635 (fax) Circle #105

See our ad on page 71.

Melmark

Wayland Rd Berwyn, PA 19312 (610) 353-1726 (610) 353-8528 (fax)

Circle #69 See our ad on page 113. **Mentor Urology**

5425 Hollister Ave Santa Barbara, CA 93111 (800) 328-3863 (805) 967-7108 (fax)

Pro Battery Specialists

890 W 23rd St Hialeah, FL 33010 (800) 572-4888 (305) 884-3483 (fax) **Circle 1,49**

See our ad on page 80.

Rhamdec, inc./Mydesc Division

476 Ellis St Mountain View, CA 94043-2240 (415) 965-3251 (415) 965-2240 (fax)

(415) 965-2240 **Circle #37**

See our ad on page 97.

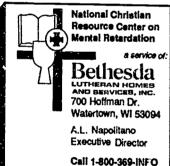
Sportime Abilitations

One Sportime Wy Atlanta, GA 30340 (800) 850-8602 (800) 845-1535 (fax)

Circle #23

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- □ Are you looking for appropriate services for yourself, your family member or client?
- ☐ Would you like to obtain information on religious services and materials offered by specific faith groups and Bethesda?

Then call our toll-free botline 1-800-369-INFO. We offer:

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Circle #84

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Market Place

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NMEDA member. Owned by person
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NMEDA member. Owned by person
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(Listings continued on next page)

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Handicap Mobility, Inc. is the premier installer and service center for vehicles with adaptive equipment in Southern New England.

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Financing is available. NMEDA
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Drive-Master, Inc.

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(201) 808-9709
Full service mobility center, raised
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Ricon, IMS, EZ Lock, and EMC
touch pad systems. 41 yrs. of service to the disabled community.
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51 Karo Road
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New-Used-Trade-Lease-Buy. Full
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We carry products from the following manufacturers: Braun, KneeKar,
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New/used van conversions, raised
roof & doors, Braun lifts & tie-downs
installed by certified technicians.
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NMEDA member.

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Fairfield, NJ 07004
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Mobile Tech., Crow River lifts,
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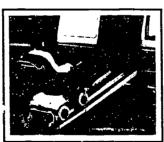
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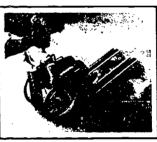
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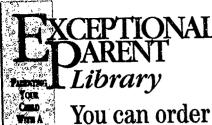
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HELPI THIS KID'S DRIVING NE CRAZY!

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HP0870D

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\$29.00



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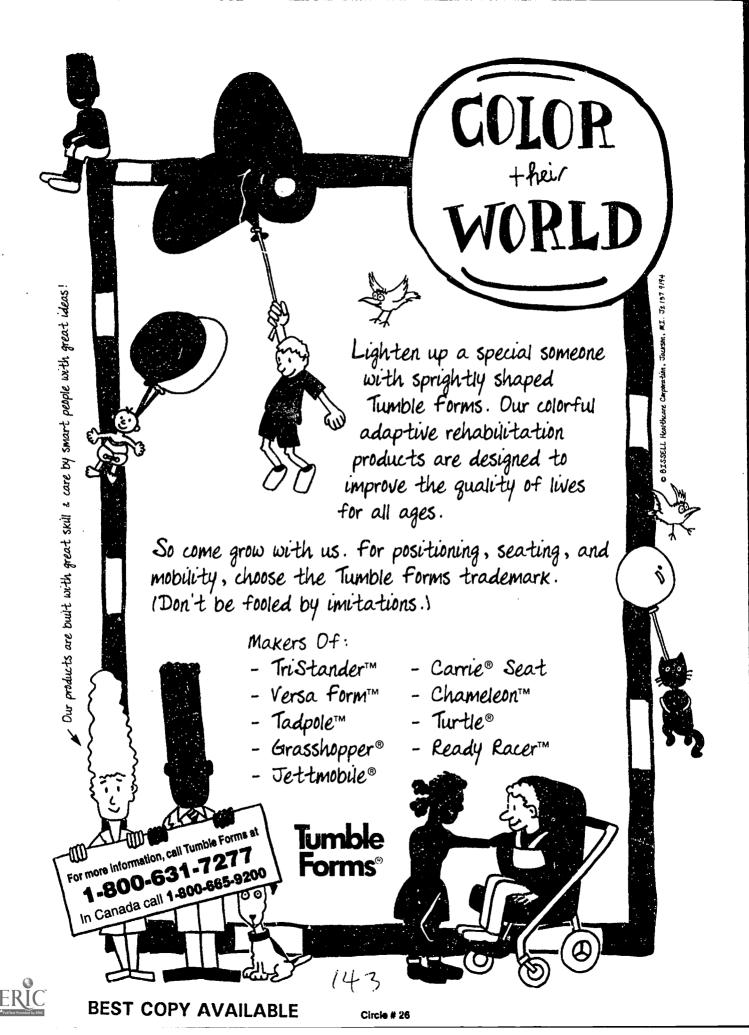
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FEBRUARY 1995

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The Magazine for Families and Professionals

EARLY CHILDHOOD

- * ASSESSMENT
- * DAYCARE
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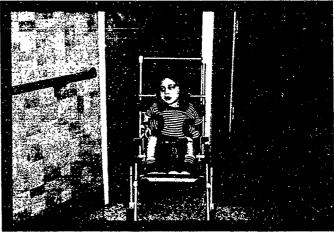
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EXCEPTIONAL DARENT FEBRUARY 1995

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DISABILITY

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COVER: Dana Reed and son Kyle, shown on the cover in a 1987 photograph (by Natalie Fobes/The SEATTLE TIMES), and above in a 1994 photo (by James May), live in Monroe, Washington with mom Debbie and brothers B.J., 10, and Jason, 6. Kyle, who has Down syndrome, is now eight years old.

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EARLY CHILDHOOD

VOL. 25, ISSUE 2

	20
The Kindness of Strangers by Betty VanHoogmoed	20
A New Vision for the Assessment of Young Children by Stanley I. Greenspan, Samuel Meisels and the ZERO TO THREE Work Group Assessment should focus on a child's interactions with trusted caregivers.	23
Daycare for Children Who are Medically Fragile by Wanda Monical	27
Making the Transition to Group Care by Mary M. Donegan, et al	29
Readers Talk About: Child Care	32
Child Care and the American with Disabilities Act	
by Rita D. Siegle	34
Child Care Resources	35
FEATURES	
Guest Editorial: All Together, Now! by Justin Dart	
Proper Seating and Positioning by Marc S. Malkin	38
DEPARTMENTS	
Editor's Desk	2
Letters	4
Search & Respond	
Fathers' Voices: My New Son by Bob Maier	17
Media: When Young Children Are Injured	
Familiar Faces	
Role Models: Irving Kenneth Zola (1935–1994)	36
Children's Health Notes	
Directory of Advertisers	46
New Products	51
Ask the Doctor: Toilet Training	
Health Insurance Troubleshooter: SSI REJECTIONS AND APPEALS	
Informational Forum: Networking	55
What's Happening	57
Exceptional Parent Library	58
Children's Page: ALEX'S PHONE CALL by Doug Bittle	60

EDITOR'S DESK

Te have come a long way from the days when parents of infants with special needs were given but two choices—take your baby home and "accept," or "place" your child. Neither choice served the needs of families or offered

STANLEY D. KLEIN, Ph.D.

hope for the future. Today, there are far more positive choices and opportunities. For many infants, young children and their families, participation in early intervention and preschool daycare programs are essential beginnings.

As parents and professionals work to provide optimal opportunities for children to thrive, they need to determine the best ways to utilize resources to meet a child's special needs. This is a neverending, challenging and complicated process requiring respectful, ongoing collaboration between parents and professionals—another challenging and complicated process! But because we, as

humans, wish our lives and decisions were less burdensome, we are attracted to quick and easy answers. This is true of our efforts in early childhood programs; we want to know exactly what to do (assessment), get on with doing it (intervention), and move on to next step (transition)! It is as if we believe everyone knows how to help children grow into empowered, productive and joyful adults, or that we believe we need not be concerned because some automated teller will deliver whatever is necessary.

With the help of creative, energetic parents and professionals from Texas to Nova Scotia, this issue illustrates the beauty of inclusive early childhood programs that are carried out with careful assessment, collaboration, training and appropriate interventions. At the same time, articles on assessment and transition, along with positive and negative stories of real children in real programs, demonstrate that while nurturing all children is hard work, nurturing children with special needs is even harder. Accordingly, when our efforts are not as successful as we wish, let us not blame a child's disability, parents' perceived inadequacies or even professionals' lack of training. Instead, caring parents and professionals can learn from one another and from the children and move forward.

Our goal is to help parents become better consumers and to allow them, along with health and education professionals, to benefit from existing know-how and to work to improve current options and to create new and better choices for children and families.

Mixed messages

Although most of this issue is up-beat, the *Guest Editorial* and *Networking* from the NPND are wake-up calls to all. Thoughtful public policy leaders—people with disabilities and parents—warn that the mood in Washington may be dangerous to children and young adults with disabilities and their families. Once again, it is time to educate political leaders so they can appreciate that the opportunities and choices for parents and children described in this issue have an important history and have evolved because dedicated parents and professionals have insisted that public attitudes change and barriers be removed.

Unfortunately, these messages have forced us to postpone our December promise to report on the failed congressional health care reform proposals that reflected the concerns of people with disabilities, family members and professionals.

Remembering Irv Zola

In February 1994, we initiated a new regular department—*Role Models*. In each subsequent issue, adults with disabilities have shared their personal stories, hopes and dreams. In this issue, we mourn Irving Zola's recent death while honoring his distinguished life by sharing a small sample of his powerful writings. Readers throughout the world can learn from his model.

Korron in Cultur Stanley D. Klein, Ph.D. Professor of Psychology, New England College of Optometry

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53 Report

Outcomes: Posture, function, and mostity improved.

Comments: Bobby shows greater endurance and activity in the GS Cushion and Back.

May 94

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

NOV.93

Jay GS: Simple, cost-effective children's seating.

Before: Tot. 92

LETTERS

A Few Miles on the Ol' Rocker

Thanks to Edward Sample for his Fathers' Voices piece, "A Few Miles on the Ol' Rocker" (December 1994). I am one of those people who call needing information about children. The other day I made a call and a father answered. I scheduled the appointment for the family interview with him. He was very clear about intending to be a part of the process.

Why do we ask for the mother when we call or visit? Probably because she is the one who usually is there; probably because that's the way we've always done it; probably because if we regularly include dads, we have to work overtime and thus take away from our own families. The probabilities could go on forever, depending on the individual caller and family.

Please know that most of us under-

Correction: The phone number listed for the Episcopal Church's Diocesan Office on Ministry with Persons with Handicaps was incorrect in the December 1994 issue. The number is (612) 721-1103. EXCEP-TIONAL PARENT apologizes for the error. stand the importance of an "intact" family. We appreciate the moral, physical and financial support that fathers and mothers give to each other and, therefore, are better able to give to their children.

Thank you again for calling our attention to our need to be ever sensitive to each family situation.

--Patsie L. Williams, LCSW-C Chief, Div. of Developmental Disabilities, Baltimore County, Dept. of Public Health, Maryland

Religious Participation

How encouraging it was to read your December (1994) issue focusing on "Religious Participation for All." Your selection of authors covered a wide spectrum, and the clarity of their message is just right for us to share with religious leaders who are uninformed.

I particularly like the title of one article, "Catholic Life for Children with Disabilities." It implies more than services provided; our spirituality influences every aspect of life. Parents and siblings are renewed in their own faith when they see a person with a dis-

Tell us about...

...talking to your child about his or her disability.

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.

ability welcomed into their religious community. You have provided a vital service to families by encouraging them to see religious experience as an important part of all their lives.

—Sister Rita Baum Ministry With People With Disabilities, Diocese of Palm Beach, Florida

☐ Congratulations for your courage in taking a great step forward and asserting the importance of "faith" as we attempt to address all areas of a person's life! What a beautiful link your magazine's issue on religious participation (December 1994) will be to educat-

PARTENT PARTENT PARTENT The Magaziner for Frankline and Professionals Note: Camp. Add: The A.
- ➤ To reach out to parents of children with disabilities and special health care needs.
- **▶** To empower mothers and fathers by providing practical information and emotional support.

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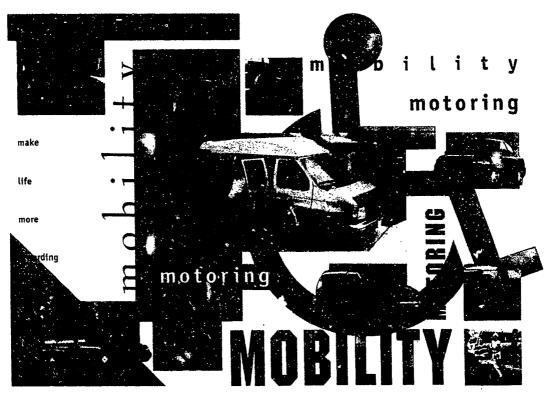
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ing professionals, parents, consumers and the community alike to the holistic needs of each person.

Nudes also to the committee chaired

Kudos also to the committee chaired by the Rev. Bill Gaventa for taking the initiative to present the topic of religion with excellence.

As a parent of a beautiful 16-year-old daughter with disabilities (and also a professional), religion is the most integral part in my family's stability and growth.

Thank you on behalf of my family and the families we represent.

—Grace Bapst Director of Church & Community Development, Agape Parents' Fellowship, New York

EDITOR'S NOTE: Agape Parents' Fellowship, based in Blasdell, NY, is an inter-denominational organization dedicated to parents and families of people with disabilities.

DO-IT

The DO-IT program, as described by Dr. Sheryl Burgstahler (November 1994), certainly seems to be an exciting program. However, missing from the program, or the article, is a description of the steps being taken to link these children with adaptive/assistive technology-related service providers in their communities.

In these times of shrinking federal programs, some sort of continuity must be ensured so these children have options when grant funding expires. It seems a bit cruel to turn these kids on to possibilities and then shut the door in their faces when federal funding is no longer available. This is particularly true for children in rural areas where technology exposure is minimal.

I certainly hope these issues are being considered by DO-IT as well as other disability-related federal programs.

-C.B. Washington

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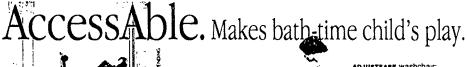
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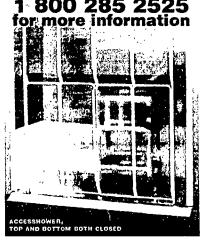
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SEARCH

Encephalocele/Microcephaly

Our two-year-old daughter, Emily, was born with microcephaly and an encephalocele on the top of her head. At three months, she had surgery to close the encephalocele. At seven months, she developed hydrocephalus and needed a VP-shunt. Emily also has a seizure disorder and bilateral optic nerve hypoplasia.

We are looking for a family who has a child like Emily or anyone else with information on this rare form of encephalocele.

J.H & T.H., Missouri

Krabbe Disease

My 16-month-old son, Troy Nathaniel, died in December 1992. He was diagnosed with Krabbe disease. All his genetic tests were normal. The doctors could not prove he had this disorder. They can't tell me if children I might have in the future will be affected by the same condition.

I want to know if anyone has had any experience with this condition. I don't trust the doctors' diagnosis and feel like they just gave up on my son.

R.M., North Carolina

EDITOR'S NOTE: The United Leukodystrophy Foundation (2304 Highland Dr., Sycamore, IL 60178, 800/728-5483) and the National Tay-Sachs and Allied Diseases Association (2001 Beacon St., Ste. 204, Brookline, MA 02146, 617/277-4463) can provide information about Krabbe disease and can put you in touch with other families.

Goldenhar Syndrome

I am the parent of a 14-month-old son. who has been diagnosed with Goldenhar syndrome, a cranio-facial disorder. Jordan was born with one eye, one ear, a mid-line cleft lip and palate, congenital heart defects, imperfections of the spine and skull malformations.

I am having trouble getting Jordan

services; for example, he needs to be fitted with a glass eye. People are very cruel. I would like to correspond with a parent who has a child with Goldenhar syndrome or similar problems.

D.R., Saskatchewan, Canada

EDITOR'S NOTE: The 1995 EXCEPTIONAL PARENT RESOURCE GUIDE lists the following US group dealing with your son's condition: The Goldenhar Symdrome Research & Information Fund, 8829 Gleneagles Lane, Darien, IL 60561, (708) 910-3939.

In Canada, AboutFace (99 Crowns Lane, 3rd Fl., Toronto, ON M5R 3P4, 800/225-3223), a support group for individuals and families dealing with cranio-facial disorders, may be able to put you in touch with local resources.

AVM of the Vein of Galen

Our seven-year-old daughter was diagnosed at birth with a cerebral arteriovenous malformation (AVM) of the vein



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of Galen. We want to hear from parents who have dealt with this type of AVM.

M.E. & O.E., Taxas

Down Syndrome and ADHD?

Our four-and-a-half-year-old son, James, has Down syndrome. His teachers and other professionals consider him very high-functioning. At the same time, they say he may have attention deficit hyperactivity disorder (ADHD) because he is very active and always full of energy—a typical "class clown."

A psychologist who evaluated James six months ago thought he was too young to be put on Ritalin, but should be reevaluated in a year. We agree that James is active, but are not sure Ritalin or other drugs are appropriate. We are afraid of trading James' playful personality for a better-behaved child.

We are looking for anyone who has experience with a Down syndrome child who has also been diagnosed with ADHD. We have read everything we can find on ADHD, but as we all know, the rules change when the child also has Down syndrome.

J.G. & J.J., Ontario, Canada

EDITOR'S NOTE: Editorial Advisory Board member Siegfried M. Pueschel, M.D., Ph.D., M.P.H., responds: "My colleagues and I are following a number of children with Down syndrome who also have attention deficit hyperactivity disorder (ADHD). There is no rea-

Search and Respond is an opportunity for readers to exchange information about their experiences meeting the everyday challenges of life with a child or young adult with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:

Search or Respond, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5006, Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in Exceptional Parent's 1995 Resource Guide (January 1995).

son why these two conditions cannot co-exist. However, it is important to make sure that environmental conditions, family stressors and/or emotional problems are not causing the observed problems. If not, and if behavior management approaches are not effective, one may consider "stimulant" medication, such as Ritalin or Dexedrine. A number of children with Down syndrome and true ADHD have

responded well to Ritalin.

"In children with mental retardation, a diagnosis of ADHD should be made only if the child's attention skills and/or activity level are clearly inappropriate for his or her developmental level. If the decision is made to use Ritalin, one should start with a low dose and gradually increase the dosage if needed. It is important to monitor the child's behavior closely."

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Self-Catheterization

D.R. (October 1994) was looking for help for a friend whose 10-year-old daughter with spina bifida needed to learn how to catheterize herself. Her inability to self-catheterize limits her participation in spontaneous activities with friends and family. I am an 11-year-old girl with spina bifida. I started doing self-catheterization when I was six or seven years old.

At first, I felt a little bit nervous. It was kind of embarrassing because I had to do it in front of the nurses, but it wasn't that hard. It did not take very long to learn—only two days!

I felt very happy to be able to do the catheterization by myself. I felt a lot better because I could go out and do more things. I did not have to stay home. Your friend's daughter can do it, too. I know she will do fine.

C.D., New York

☐ I want to recommend a wonderful booklet called *Toobie: A Self-Cath Coloring Book for Boys & Girts.* English and Spanish versions are available free from Mentor Urology, 5425 Hollister Ave., Santa Barbara, CA 93111. Write to them or call their customer service number, (800) 258-3480.

B.M.K., New Jersey

EDITOR'S NOTE: In addition to the free coloring book recommended above, Mentor Urology produces and sells other educational materials on intermittent self-catheterization. These include videotapes, flash cards and a parent guidebook.

Stepparent Seeks Insurance Information

M.S. (November 1994) has a five-yearold stepson with cerebral palsy, spina bifida and multiple, congenital, physical anomalies. Because Chris' father has left the military, Chris is no longer covered under the US military medical plan. Despite the fact that Chris' birth problems have all been corrected to the extent that they can be, his parents have been unable to find insurance companies that will cover him because of his "pre-existing conditions." M.S. wanted information on insurance plans that cover children with disabilities for the "normal" childhood illnesses and injuries. M.S. also wanted to correspond with parents who have a child with similar conditions, or other stepparents of children with any disability.

I, too, am the stepmother of a child with special needs. My nine-year-old stepdaughter, Robin, was born with a number of problems including severely clubbed feet, no anus, no bladder or urethra and a tethered spinal cord.

Being a stepparent is difficult in and of itself, let alone when there are complexities such as a child with disabili-

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ties. There are few role models for stepparenting and I think the stepparent's role depends a lot on family circumstances. In our case, Robin travels back and forth between her parents' houses every few days, a schedule initially necessitated by her intense medical needs. My role is not as active as is it would be if Robin was with us full-time.

It has been a struggle for me to find my place. Robin has been very ill for about three of the four years since our marriage. She has had four major, unanticipated surgeries. There was a period when she was totally incapacitated with pain and no one could find a reason. All of these circumstances have put stress on my relationship with my husband and made it difficult for me to establish a relationship with Robin.

On the insurance front, I do have a couple of suggestions. The state of Wisconsin, where we live, runs a risk-sharing pool for individuals denied coverage by a commercial carrier. The premium is high, as is the deductible, but it provides coverage even for medical problems associated with a disability. Other states may have similar programs. Also, HMOs often accept individuals without a pre-existing condition limitation or medical certification, if coverage is part of a group policy. C.M.E., Wisconsin

 As the parent of a child who has cerebral palsy, asthma and gastrointestinal problems, I also had difficulty finding insurance after his group policy expired. Like M.S., I live in California. I was fortunate to find the California Major Risk Medical Insurance Program, 818 K St., Ste. 200, Sacramento, CA 95814, (916) 324-4695 (voice), (916) 324-4878 (fax).

This program gave me a choice between five carriers with varying deductibles, benefits and pre-existing condition clauses (usually a three-month waiting period). Eligibility is based on proof that you or your child has been denied insurance coverage.

M.K., California

Disability Awareness in Public Schools

M.G. (October 1994) has a 10-year-old son, Allan, with Asperger syndrome (a type of "high-functioning" autism) and some neuromuscular problems. He does well in regular science and social studies classes. M.G. wanted to hear about disability-awareness programs that have been used successfully in public schools to teach kids about disabilities.

I am involved with an organization called Kids On The Block (KOTB). The "kids" are a troupe of almost life-size puppets, with and without disabilities, designed to teach school-aged children what it is like to have a disability or to

Most KOTB troupes are manned by volunteer, communitybased organizations. The program includes a teacher's manual, pre-performance activities for the children and followup. Some troupes offer performances dealing with a specific disability; others cover a range of topics.

KOTB troupes perform throughout the US, Canada and 20 other countries. You can obtain more information and a list of troupes in your area from the KOTB national office, 9385-C Gerwig Lane, Columbia, MD 21046, (800) 368-5437 (voice), (410) 290-9095 (voice), (410) 290-9358 (fax).

N.M., Ontario, Canada

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All Together, Now!

by Justin Dart

E WHO HAVE DISABILITIES and our loved ones are in grave danger of losing our fragile, hard-won beachhead on the mainland of American life. There is an escalating chorus of assaults on the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), Medicaid and SSI

with Disabilities Education Act (IDEA), Medicaid and SSI supports for children with disabilities. The new congressional leadership has announced their agenda—a "Contract with America"—that, if implemented literally, could drastically cut virtually all the programs that empower us. They speak of "erasing" key economic and social programs of the last three decades, and "reasserting American

culture as it has existed for the last 300 years"—a culture in which people with disabilities were outcasts.

I cannot believe that the leaders of our nation—Republican or Democrat—are scheming to destroy our rights. But when I see the current eruption of public frustration with the growing pains of democracy, I remember history. I am terrified that the hysteria for instant solutions and easy scapegoats could result in a move to pull the plug on our progress, our rights, the programs that empower us and, in some cases, our very lives.

Republican leaders have announced a blitz to pass their "Contract" agenda during the first 100 days. We must act quickly, while basic positions are still being formed.

Reach out to all of your state's representatives and senators. Nearly half of the current members of Congress were not present during the ADA debate in 1990. In too many cases, their perceptions of disability-related laws and programs have been formed during the recent avalanche of negative propaganda. Many Capitol Hill veterans, including old friends in both parties, have also been influenced by these messages.

Don't discount the potential support of new conservative members of Congress. Many are people of profound conscience, who share our passionate determination to emancipate all prisoners of dependency and empower them in the mainstream of free-enterprise democracy.

Our messages, our power

We have messages to deliver—to the Congress, but also to state houses, to the White House, to business, to labor and to groups representing minorities, women and older Americans.

There are many ways to deliver our messages—face-toface or by telephone, fax, computer or mail. Use the media. Be visible at public events with signs and questions. Flood talk shows and newspaper letter columns. Communicate personal stories illustrating the necessity of the ADA and IDEA and their positive effects.

These are the messages we must deliver:

• Disability impacts everyone. Sooner or later, every family will experience disability. Public policy that fails people with disabilities fails every family. We who have disabilities form one fifth of the population—49 million

Americans. Add in our families and service providers. We all vote.

- The ADA is good for America. The ADA is not a costly, unfunded mandate. It is a civil rights law that extends equal constitutional protections to Americans with disabilities. The ADA will not bankrupt anyone. It specifically provides that no business or public entity can be required to do anything resulting in undue hardship. The ADA will open the doors of opportunity, enabling us to get off welfare and into the productive mainstream. The ADA will pay for its tiny cost a hundred times in terms of reduced welfare and increased productivity.
- No ADA amendment! We will cooperate fully to ensure that ADA implementation is sensitive to the needs of individuals, businesses and communi-

ties. But we will fight any weakening amendment. We will fight for our right to be fully equal citizens.

• Contract with America, Contract of the people, by the people and for the people—all the people—yes! Contract on Americans with disabilities, no! Social and economic programs need improvement. No group is more aware of this than people with disabilities. But let us be careful that in our haste to change things, we do not create more welfare, more paternalism, more costs and more misery.

Let us ensure that changes protect and enhance all the programs and laws that empower people with disabilities of all ages to be productive participants in the mainstream. Let us ensure that changes empower people with very severe disabilities to be free from the fear of rationed life, to be emancipated from expensive, prison-like institutions and to live with dignity in their communities.

• The American heritage at its best—the power of America's success, since 1776—has been the aggressive



Justin Dart (left) speaks with President Bill Clinton about health care reform at the White House in May 1994.



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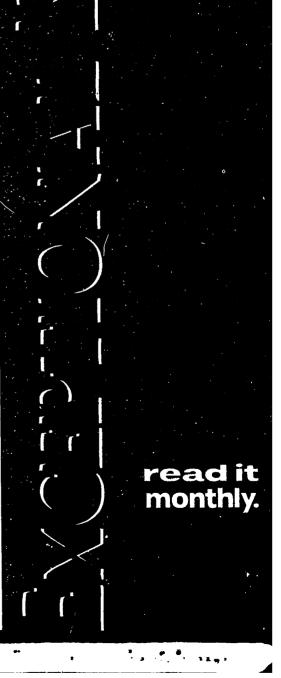
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Dart (seated, third from left, wearing hat) joins other disability-rights activists heading toward the Lincoln Memorial as part of the "Bridge to Freedom March" for health care rights in May 1994.

empowerment of oppressed people to be fully equal participants in the mainstream of free-enterprise democracy. Nothing could be more Republican, nothing could be more Democratic, nothing could be more in harmony with family values, nothing could be more profitable, nothing could be more positively American than the empowerment of Americans with disabilities.

Unity

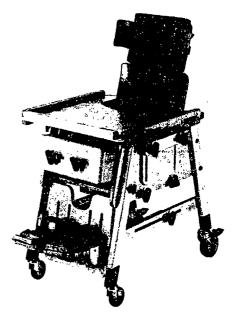
We have the ultimate weapons to win this battle for a just society. We have the moral and the economic arguments. We have people who have created miracles of independence and justice. We have each other.

If we can use the coming policy debate to establish principles of empowerment, if we can exploit the coming power struggles to create new political clout, if we can survive the coming test of fire with our principles and our passion intact, we will have established a foundation on which future generations in this and every country can build the edifice of democracy for people with disabilities.

We must set aside politics as usual, and unite in action—people with disabilities, family members and professionals. This will not be easy. Funding cuts invite cutthroat competition among us. The polarization of mainstream politics invites us to attack each other. Divide and conquer will be the strategy of our opponents. We must master the art of complementary unity, playing different roles in total harmony for the same goals—equality, independence and empowerment in the mainstream.

America is watching. The world is watching. Will our movement unite in action? Will we increase our advocacy enough to keep the dream alive? If we fail, God help our children in the 21st century when leaders say, "America tried equality for people with disabilities, and it didn't work. Why try it again?"

Justin Dart has founded and served as CEO of three successful businesses. A long-time, human-rights advocate, he has served five presidents in the area of disability policy. He recently resigned as chairman of the President's Committee on Employment of People with Disabilities to become a full-time advocate for the civil rights and empowerment of people with disabilities.





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FATHERS' VOICES

My New Son

by Bob Maier

I feel so confused, hurt and utterly sad. The child I thought was mine is gone.

I want to cry.

Cry for the child who will never ask, "Why?"

"Why do the leaves turn red in autumn?"
"Why do I have to go to bed right now?"

"Why are you crying, Daddy?"

Son, what will you be when you grow up? I once thought you might be a zoologist, traveling to exotic places,

studying the rare and wonderful animals you've always loved.

When you were less than a year old, sitting motionless,

listening to Mommy's choir sing,
I dreamt that someday you would be a
creator of beautiful music.

My child has been taken from me!

But that can't be.

He's here with me now.

He hasn't changed.

Yet still, I feel as though he's gone.

ne s gone.

My child has somehow died.

The child of my dreams

and hopes is no more.

I know these feelings are normal and helpful, that I shouldn't feel guilty

for having them.

All the experts tell me this. But it doesn't help the pain.

Things are getting better now.

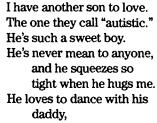
The funeral for the child of my expectations is over now.

[From top to bottom] Bob enjoys a hike in the Cascade mountains near the family's home with two-year-old Karl. Bob and Deborch Maier hold their sons (from left) Karl, 5, and Keitis, 3. One of Karl's favorite pastimes is throwing rocks into the water of local streams and ponds.

Oh, I still visit the cemetery from time to time.

I put Cub Scout caps and grade-school science projects at his grave.

But I don't spend so much time there anymore.



and he gets such a cute smile on his face when he says, "I did it!"

He's still the same boy who loves monkeys,
Peter Pan, kiwi fruit and throwing rocks in the water.

I'm learning to love my new son, and he has always loved

and he has always loved me.

Bob Maier works as a fisheries biologist for the federal government. He lives with his wife, Deborah, and two sons—Karl, 6, and Keith, 4, in Edmonds, Washington. Bob wrote this poem soon after Karl was diagnosed with autism at age three.

Karl is now fully included, with the help of an aide, in a regular kindergarten class at his local elementary school. Recently, to his father's surprise and delight, he has started asking his first "why" questions.

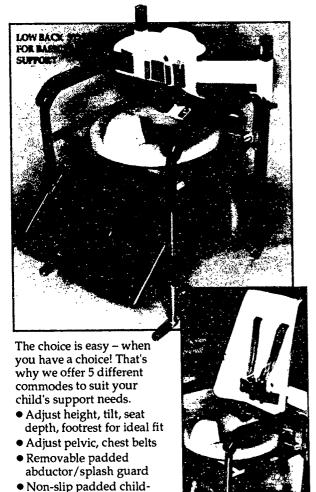
Bob's favorite activity is picking blueberries with his family in the early autumn sun of the Cascade

mountains near their home. Karl's favorite activity is bouncing on his trampoline while watching Disney videos.



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MEDIA

WHEN YOUNG CHILDREN ARE INJURED: FAMILIES AS CARE-GIVERS IN HOSPITALS AND AT HOME by Marilyn Lash, M.S.W. and Jane Haltiwanger, M.A., Ed.M., is published by EXCEPTIONAL PARENT magazine and is available through

Exceptional Parent Library (800/535-1910). It is the third in a series developed by the Research and Training Center in Rehabilitation and Childhood Trauma, Department of Rehabilitation Medicine, Tufts University School of Medicine, New England Medical Center.

The guide has many examples that demonstrate that the family is the major support in a child's life before and after an injury. The following is an excerpt from Chapter 3, Helping Siblings: Needs and Reactions.



Suggestions for helping siblings

- Stay in touch. If hospital visits prevent you from seeing your other children daily, set up regular times to talk on the phone. If they are being cared for by others, send tape recordings of songs, bedtime stories or messages to them...
- Make time for questions. Siblings will have many questions, but they may not always ask them directly. They need someone to explain what has happened. It helps to repeat information, since changes are confusing and unsettling...
- Keep explanations honest, simple and concrete. When children ask questions that you don't know how to answer, let them know that you will find out. Then go back and explain in words they can understand. A good rule of thumb is to give descriptions, not interpretations.

For a child in a coma, instead of saying he is "peaceful" or "sleeping" or "can't hear," try saying, "His eyes are closed and he breathes very quietly. When I talk to him, he does not answer me." If a child asks, "Can he hear me?" you can answer honestly, "I'm not sure."

- Communicate with teachers of siblings at school or day care. Siblings need the support of their teachers and friends. Teachers will be more understanding and responsive when they are aware of the situation.
- Include siblings in care. You can teach siblings how to help... Even very young children can hand objects needed for care or open/close the curtains. Use actions and words that show a quiet, confident approach to touching, loving and caregiving. This helps siblings overcome their fears, reluctance or embarrassment.

FAMILIAR FACES



"Isn't it ready yet?" A hungry Theresa Marie Stevens, 21 months, waits patiently for Mom to finish preparing her lunch. Theresa, who has cerebral palsy and epilepsy, lives in Port Royal, Virginia.



Ole Sorensen (right), 12, shares a raft with Victoria and Erika Houle as the friends enjoy a summer day on Lake Superior at a beach near their Washburn, Wisconsin homes. Ole and Erika first met as HeadStart classmates; now Erika's mom is Ole's respite care provider. Ole has autism.



It must be puppy love! Rachel Blecha, 3, takes all the kisses she can get from her beagle puppy, Rose. Rachel, who has cerebral palsy, lives with her mom, dad and baby brother, Kule, in Kewaskum, Wisconsin.

you like to share a foverthe candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, Exceptional Parent, 209 Harvard Street, Sulie 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

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During early childhood, children first confront challenges they will work on for the rest of their lives—interacting with the world, learning new things and getting along with others. All children, in all cultures, with or without disabilities, face the same developmental tasks. At the same time, each child draws on his or her individual strengths to meet these challenges. The stories and articles in this special section emphasize these two important messages—all kids need the same things, and all kids need different things.

To reach their full potential, all children need stimulating, caring environments where they can experience success and mastery. Many preschoolers will spend large amounts of time in a group care setting. Some articles in this section focus on child care options and the characteristics shared by successful programs. As each shows, nurturing caregivers are essential, but not sufficient—children also have individual needs requiring individual attention, even within a group care setting.

Meeting the specific needs of individual children means paying attention to issues of assessment and transition. "A New Vision for Assessment" and "Making the Transition to Group Care" provide guidelines and suggestions for these ongoing processes. Sidebars illustrate the successful results of careful attention to individual needs-inclusive child care that works for children with and without disabilities. (We are grateful to SpeciaLink, the Canadian network of inclusive child care providers, for sharing these stories with us. For more about SpeciaLink, see page 35.) "The Kindness of Strangers," demonstrates inclusive child care is important for parents, too. These stories also remind us that young children have much to teach adults.

This section includes an article about the Americans with Disabilities Act (ADA). People tend to think of the ADA as a civil rights and equal employment law for adults with disabilities. The ADA also benefits very young children.



The Kindness of Strangers

by Betty VanHoogmoed

h, this has got to stop! I had just picked up my son from daycare and as the imter's supervisor began to brag about how well Jake was doing, my eyes welled up with tears. Again. But I just can't help it. The focus on my son used to be so negative. These positive, happy stories overwhelm me.

Undiagnosed

Jake has some sort of developmental problem, as yet undiagnosed. When he was a baby, do fors told us he was blind. Since then, although medical professionals still don't know why, his vision has gradually and miraculously improved. Jake is now two and a half years old; his visual acuity is much better, but he still does not walk or talk. He has some fine motor problems, too.

Understandably, Jake's problems have been a major focus for us, as well as for many medical experts, social workers, friends and relatives. In his short life, Jake has been examined by ophthalmologists, neurologists, geneticists, metabolics experts, dermatologists and audiologists.

My husband and I have filled out endless forms and repeatedly answered the same questions. My nine months of pregnancy have come under scrutiny, as has the past century of our relatives' health. Jake has been photographed, videotaped and examined some more.

Though we worried that Jake's many encounters with poking and prodding medical professionals would traumatize him in some way, the search for a diagnosis could not wait. Some conditions, especially metabolic disorders, could be successfully treated if diagnosed early.

With every test, we hoped we would get an answer. Once we had a diagnosis, we could do more for our son. We could read the literature on Jake's condition. Contact other fami-

lies who have lived with it. Answer questions. Educate others. Get a glimpse into the future. The moment parents are given the name of a child's disorder—no matter how terrifying that diagnosis may be—they begin to deal with it.

A "negative" focus

During the first two years of our child's life, it seemed that every interaction involving our son emphasized only the things he was unable to do. This negative focus came not only from doctors and social workers, but also from well-meaning strangers, relatives and friends—"What's wrong with him? Is he doing this yet? Have you tried this? When is he going to walk?" The questions and comments stemmed from concern, but they—as much as Jake's puzzling disorder—robbed us of the joy a new baby should bring to a home.

It was such a sad time—those first two years. We knew Jake had a problem but we didn't know what it was. We didn't know where to turn. We didn't know what to tell people. Access to services was often dependent on a diagnosis, which we obviously didn't have. We wanted an answer but we hated putting Jake through the testing. We needed help but resented the fact that we couldn't just close our front door and be a family. Living far from a major metropolitan center, support systems were minimal. I kept looking for people to help us, but nobody knew how. I wanted to talk about our experiences-but nobody understood.

In the midst of this swirling mass of questions was a little boy who puzzled, frightened or saddened those around him. Few people seemed able to enjoy him. Even I was obsessed with getting him to the next developmental phase. I loved my son and I played with him often, but teaching was always my motive.



Most people fell into one of two groups—knowledgeable professionals whose time, and often compassion, was extremely limited, and people who cared deeply about our little family but really didn't know seemed like a good solution, but I was nervous about it.

Jake didn't trust many people probably a result of all the medical testing he had endured. And he would be the first "special needs"



how to help. The first ray of sunlight came last year. Jake's new physical therapist was the first professional who had ever seemed able to enjoy and help our son without being so bewildered about the nature of his disability. She accepted Jake just as he was, complimenting his wobbly stance while working on ways to improve it. As I watched her praise and play with him, I fought to control my tears. It was the first time I had seen professionalism meld with compassion, and the sight awed me.

Beginning daycare

The second ray of sunlight turned out to be Jake's three-morning-a-week enrollment in daycare. The role of teacher/therapist/new mom had become too much for me. I felt so inadequate as the primary source of stimulation and guidance for my two-year-old son. Part-time daycare

child to be integrated into the small daycare center. Jake would have his own resource teacher; I liked her, but I was just as worried about Jake being treated differently as I was about him being treated the same.

I refused an assessment. I even withheld medical data—after all, he had no conclusive diagnosis. I just told his resource teacher to get to know him. She would discover the extent of his limitations soon enough.

In the beginning, Jake became very upset when I dropped him off. Once I could peel myself away from my sobbing child, I often stayed and watched through the one-way glass. And I liked what I saw.

Learning to trust

Before Jake started daycare, I cried many tears of frustration, rage and raw hurt. My tears had less to do with Jake than with my being thrust into such a new, frightening world and taking on the unfamiliar and very challenging role of teaching a child with disabilities.

Now, however, I am feeling

stronger. The future looks more hopeful, and these days, the tears I shed are tears of happiness. The love of so many people for my son has softened my heart, and my tears. The kindness expressed toward him is so positive, so hopeful and so new.

I find myself overwhelmed by things most people take for granted. Witnessing the "real world" of childhood is so very touching—playing with toys, coloring, sharing, dressing up. All these common elements of childhood were, until now, so alien to my son, and to me. On the other side of the one-way glass, I often get teary-eyed when I see the children play. Not because my son isn't part of the activity—but because he is.

Give me an incompetent expert, an insensitive question or a tactless doctor and I'm ready. I've become quite a good fighter over the past two years.

But give me paper with paint splashed all over it and Jake's name at the top and I dissolve into a moisteyed display of gratitude and wonderment. Tell me my son fed himself 10 french fries at lunch. Share a funny story about his participation in a game. Tell me how much the other children enjoy his company, and I can't hold back the tears.

My son is loved and cared for by people who were strangers just a few months ago. But what touches my heart the most—and gives me faith about the future—is that my son has finally learned trust.

And, looking back, I realize he isn't the only one.

Betty VanHoogmoed lives in northern Ontario, Canada with her husband, John, and their three children. Although you won't catch her baking cookies or trying to get her "whites even whiter," Betty describes her primary role as "mom" since hanging up a checkered career in media.

Jake, now three and a half, attends daycare five full days a week. He walks and is learning to communicate through sign language and some speech. His family and friends consider his lack of diagnosis secondary to everything else happening in his life.

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A New Vision for Assessment

hoices about the best ways to serve the needs of young children and their families are made on the basis of a process called "assessment." The purpose of assessment is to learn about and understand the unique needs of each child "in context"—within his or her family, community and culture. In practical terms, this means deciding how to use resources most effectively to help each child grow and develop and to help his or her parents plan for the future.

ZERO TO THREE/National Center for Clinical Infant Programs, with the support of the A.L. Mailman Foundation, has convened a distinguished group of clinicians, researchers and parents to develop basic principles of assessment that can guide practicing professionals and enable parents to become more knowledgeable consumers. This article, written by Stanley I. Greenspan, M.D., Samuel Meisels, Ed.D. and the ZERO TO THREE Work Group, has been adapted with permission.

Developmental assessment is a process designed to deepen understanding of a child's abilities, and of the caregiving and learning environments most likely to help a child make fullest use of his or her developmental potential. Assessment should be an ongoing, collaborative process of systematic observation and analysis. It involves formulating questions, gathering information, sharing observations and interpreting information and observations to come up with new questions.

An assessment consists of a "snapshot," or series of snapshots (samples), of a child's knowledge, skills, abilities or personality characteristics. These snapshots are taken at a particular time, from a particular vantage point and with a particular instrument or recording device. An assessment approach that does not represent a child's day-to-day life will not be meaningful. This is particularly important with very young children, because the first three years of life are a period of such immense change, growth and development.

Limitations of current approaches

Under pressure to act quickly, professionals may approach assessment in a fragmented manner, rather than performing assessments that reflect full understanding of a young child and his or her relationships within the family, community and culture.

Under pressure to produce quick "scores," professionals may use procedures that were developed for older children. These can often yield misleading information. They are not built on a model of how the infant and young child develops within the family and do not reflect an understanding of the specific types of difficulties and developmental challenges that children and families face in the first three years.

There has also been a tendency to assess abilities easiest to measure—those for which there are tests already in existence. Assessments have traditionally put less emphasis on aspects of development that are hard to measure and have under-emphasized the social

contexts within which a young child develops.

Assessments often overlook some abilities. This is especially true when a child has difficulties that may interfere with his or her demonstration of seemingly hidden strengths.

An assessment will be useful and accurate only if a child can demonstrate optimal abilities. This means allowing parents or other familiar adults to work with the child, using what they already know to discover more about the child's abilities and the challenges he or she is facing. Parents and professionals must observe the range of the child's skills in different contexts. The goal of assessment is not to test or to grade a child, but to learn how to best help.

Assessment should involve multiple sources of information and multiple components including:

- parents' description of a child's abilities in the different areas of development and discussions of their questions and concerns;
- parents' detailed description of a child's history;
- direct observation, including the child interacting with a caregiver;
- observations and discussions with the family about ways they have found to support the child's development and about family patterns that are of concern to them; and
- focused observations to assess specific abilities and disabilities.

This approach begins with information from family members, and then adds sources of information to help answer questions. This is very different from some approaches, in which professionals use a series of structured assessment tools (tests) to examine specific areas of development with only brief attempts to obtain a picture of the "whole" child by using information provided by family members or others.

ZERO TO THREE is the only national non-profit organization dedicated to improving the chances for healthy physical, cognitive, and social development of infants from birth to age three. Established in 1977, ZERO TÖ THREE is committed to:

- exercising leadership in communicating the importance of the first three years of life;
- focusing attention on infants' and toddlers' major relationships and off children's day-to-day experiences; and
- promoting training that fielps service providers become and remain competent, trustworthy allies for families.

For more information about ZERO TO THREE's publications on assessment, early intervention and other topics, contact ZERO TO THREE, 2000 14th St. N, Ste. 380, Arlington, VA 22201-2500, (800) 899-4301.



Appropriate approaches

• The child's relationship and interactions with his or her most trusted caregiver(s) should form the cornerstone of any assessment. A child's abilities should always be assessed in the context of interactions between child and caregiver—situations in which the child is most likely to feel secure and motivated and most likely to bring out the child's abilities.

Occasionally, the clinician may need to use his or her own interactions with the child as the basis for observations. But before the clinician interacts directly, he or she must take time to get to know the child and be sure the child feels comfortable.

• Understanding the sequences and timetables of typical development is essential. The period from birth to three is one of rapid physical growth and change. While maturation generally proceeds in an orderly and predictable sequence, there is a considerable range in what can be regarded as normal or typical. There may be considerable variation in the characteristics of a particular skill and the age at which it first appears.

To understand where a child is in his or her development, clinicians

(and parents) need to have a broad sense of the sequence (what precedes what) and timetable (the age range during which one can expect to see an ability emerge) for different areas of development. Understanding where a child is in terms of sequence and expected timetable enables adults to predict what will come next and to determine whether a skill is emerging more slowly than expected. This is better than using a "score" or "quotient" to describe a child's abilities because it allows the use of many sources of information in formulating an intervention plan.

Including Kaylee

Increasingly, children with special health care needs are Lattending regular daycare centers. Staff members must learn new skills to care for these children—from monitoring food intake to more complicated medical procedures like catheterization, administering oxygen or changing a colostomy bag.

At the Burquitlan Childcare Centre, we first faced the challenge of including a child with special health care

needs when we met Kaylee.

Kaylee was a three-year-old child with a trachecstomy—a breathing tube through her trachea that ended with a hole in her neck, covered with a removable cap the children called a "nose."

We've always felt that when a family arrives at your doorstep, you do your best to help them. Kaylee was a child who needed exactly what we had to offer—a good daycare setting. But her tracheostomy was one need we had not been trained to deal with.

The daycare center is far from a sterile hospital setting. It's full of messy, active activities—sand, water, paint and a lot of outdoor play. Kaylee was a very mobile child who was physically able to participate in all the usual activities. Compounding the challenge were the other children who were sure to be curious; we worried that another child might pull Kaylee's "nose" just to see what would happen.

Including Kaylee meant more than simply dealing with the child. We knew we would have to deal with staff training and concerns, parental expectations, liability issues and the curiosity of the other children. It took a lot of reassurance from Kaylee's parents and doctors and the Alberta nursery school she had previously attended to give us the courage we needed.

Staff training

Kaylee's parents and doctors insisted that non medical personnel could handle routine trach procedures. As an introduction, her mother demonstrated the procedures to our staff. A nurse came to the center for a more in-depth discussion. Then we went to the hospital to observe and learn the procedures.

We decided on some fundamental rules for quality practices.

For example, no second-hand knowledge was allowed. That meant one staff member would not train another to care for the trach. Training always meant going back to the source—to medical professionals.

Parents and children

Kaylee's parents wanted her to feel like a typical child with a trach, not like a "trach child." Their attitude had a lot to do with her attitude, and with our attitudes as well.

We thought about what we should tell the other children before Kaylee arrived. We finally decided that it was like "Johnny wears glasses"—you don't warn kids ahead of time that Johnny's glasses can break. We decided they only needed to know that the tube doesn't hurt Kaylee, but that they shouldn't touch it and had to be careful when playing with her in the sandbox. Kaylee wore a bandanna over the "nose" when she played in the sandbox. Soon, all the kids wore bandannas in the sandbox.

Kaylee's trach had to be cleaned several times a day, first instilled (using a saline solution from a syringe to loosen mucus) and then suctioned. Staff did these procedures in the daycare office.

Suctioning is noisy and messy—it's just like blowing any child's nose. At first Kaylee didn't want anyone to watch. But soon she was comfortable enough to have her friends accompany her to the office. They would continue their conversations while we cleaned her trach. It wasn't long before all the kids were suctioning their dolls.

Staff members agree that the extra work it took to include Kaylee was well worth it. Kaylee is currently in kindergarten. She has age-appropriate social skills because she had typical childhood experiences. And because an inclusive daycare program was available, her parents were able to keep up their careers.

-Trudy Norton and Aly Prins

Trudy Norton and Aly Prins are co-directors of the Burquitlan Childcare Centre in Coquitlam, British Columbia, Canada.



Professionals assessing a child must have sufficient experience with observing a wide range of infants and toddlers and their families. Only professionals with an excellent understanding of early development should be given responsibility for assessments that will lead to a determination of a child's developmental status and/or a plan for intervention.

- The assessment process should identify the child's current abilities and strengths, as well as abilities the child needs to develop to attain landmarks further along the developmental road map. Development proceeds in a stepwise fashion; one capacity builds on another. Our knowledge of the typical timetable for skill development can be useful. It can never be useful, however, to describe a child as being a certain number of "months behind."
- Assessment should be an ongoing collaborative process between professionals and parents. Participation should be open to everyone who is substantially involved in supporting the child and family. Parents and significant caregivers, members of a family's support networks and professionals with special expertise all have important roles to play.
- The process of assessment should be viewed as the first step in a potential intervention process. A working alliance between parents and professionals who agree about the child's strengths, vulnerabilities and challenges is essential to identifying and planning ways to support a child's continuing development.

The rapid changes that typically occur in the first three years of life make ongoing monitoring and frequent reassessment important. Careful observation of the child in multiple but familiar contexts and on multiple occasions will provide a rich picture of the child's current strengths and challenges.

When a child and family are involved in early intervention, professionals and parents should meet regularly to compare observations of their day-to-day experiences. These discussions will help team members identify new goals and promising ways to approach them.

Inclusive Child Care Benefits All Children

When my son, Scott, was four years old, he met a new friend at daycare. Quickly, Scott and James became inseparable best buddies. Although Scott talked a lot about James at home, we didn't realize James was blind until we went to a parents' meeting two months later.

I guess we should have known something was different. Scott, has always been a rough-and-tumble type of kid—not terribly interested in quiet, indoor play. His interests had always been physical—running faster, jumping higher, throwing further. But now, Scott was coming home and talking about listening—picking up the sounds of squeaking hinges or of juice being poured. He told us it was neat to use sounds to try to guess what was happening when you closed your eyes. He said James could do that real well. Scott said James wanted to be an air conditioner repairman when he grew up; now, so did Scott.

At the end of that year, James moved away. It's been four years since the boys were together. But we continue to be amazed at the combination of "tough guy" in Scott, and the care and interest he shows for people with disabilities. It's as though he very naturally sees past their disabilities, as though he sees the inner person right away. We think we have James to thank.

Having experienced the benefits of inclusive child care, we now participate in protests and letter-writing campaigns to get children with disabilities into the classrooms and summer recreation programs our children attend—we now know that experience is valuable for everyone.

---Edward Roberts

Inappropriate approaches

Some current practices have no place in an ongoing, collaborative assessment process:

- Young children should never be challenged during assessment by separation from their parents or familiar caregivers.
- Young children should never be challenged by assessment by a stranger. Unfortunately, in many settings where assessments take place, very young children are introduced to strangers and, after only a brief "warm-up" period, are expected to demonstrate their "best abilities." This is highly unlikely to yield meaningful information.
- Formal tests should not be the cornerstone of an assessment.

 Many assessments are conducted using tests that have been chosen only because they are available, or because available staff have been trained in their use. Structured tests look at what an infant can and cannot do in relationship to defined procedures. The abilities tested by formal tests are only approximations of skills the child needs to use in real-world situa-

tions; natural observations are more useful.

Many tests were developed with children who were not experiencing developmental challenges. These tests are not designed to bring out the unique abilities and potential of children with disabilities.

Conclusions drawn from misleading scores may lead to inappropriate recommendations. Compared to complete assessments of infants and toddlers with disabilities, test results often seriously underestimate children's true capacities.

Summary

The cornerstone of assessment should be observations of the child with trusted caregivers. Assessment involves multiple sources of information, organized and integrated to obtain a picture of the "whole" child. Appropriate assessments should help parents and professionals deepen their shared understanding of a child's competencies, and of the caregiving and learning environments most likely to help the child make full use of his or her developmental potential.





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Daycare for Children Who are Medically Fragile

By Wanda Monical

ere's a typical morning for Ellen and her family. Her parents are up at 5:30 a.m. Her mother packs the diaper bag and other essentials for daycare. She wakes Ellen at six for bathing and dressing. Ellen slept fitfully last night. So did the rest of the family.

Meanwhile, Ellen's father starts breakfast—making a special one for Ellen—and wakes Jenny, Ellen's older sister.

What makes this typical morning different are the "other essentials" in Ellen's diaper bag. There's not only a change of clothes, but her feeding pump, tubing, syringes, medications and a special formula. Ellen's "day-

Medical Daycare Centers

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The HUG Conter, Atlanta, GA, (404) 393-9222. Birth to five years; capacity of 18. Circle # 188

Kennikide, Kennesaw, GA, (404) 499-7291. Six weeks to six years with capacity of 18. Circle # 189

NGdStreet; Denver, CO, (303) 894-0401. Six weeks to six years; capacity of 10. Circle # 190

Oteten Kimberty Quality Cere's Center for Medically Complex & Technology Dependent Children Auburn, MA, (508) 721-2626. Four weeks to seven years, capacity 24. Circle # 191

Child Health Systems, Westwood, MA, (800) 237-2474. Operates five day centers in Florida (Tampa, Orlando, Miami, W. Palm Beach and St. Petersburg) and two in Massachusetts (Brookline and Waltham). Birth to 21 years in Florida; four weeks to seven years in Massachusetts. Circle # 192

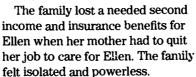
SpecialCare of Tucker, Inc., Chamblee, GA, (404) 458-5970. An educational model providing therapeutic services from birth to age 21. Circle # 193

Veertiess Pediletric Facility Voorhees, NJ, (609) 346-3300. Opening March 1995. Birth to 21 years; capacity 27 Circle # 194

Note: Use circle numbers on "Free Product and information Card," page 47.

care" is staffed by nurses and therapists, as well as teachers.

Two-year-old Ellen has cerebral palsy and gastroe-sophageal reflux. She has difficulty eating and is unable to hold her head up by herself. Until six months ago, nurses and therepists were in and out of the family's home on a constant basis.



Ellen's family is not alone. There are more than three million children with chronic illnesses and disabilities who need complicated care. This number is growing as major medical advances increase the survival rate of high-risk infants.

Families struggling to meet the needs of these children often find themselves overwhelmed. Homes become makeshift hospitals and parents become nurses. Parents never leave the kids, and often lose sleep because of the around-the-clock care the children require. The physical drain, financial pressure and isolation can have devastating effects on a family.

An alternative for families

Medical daycare or day-treatment centers offer an alternative for these children and their families. Although only a handful of these centers are now in operation in the country, interest is growing.



Photo courtesy Olsten Kimberly QualityCare, Aubum, MA.

Typical centers operate Monday-Friday from 7 a.m. to 7 p.m. Some offer after-school, weekend and respite services. Most feature indoor and outdoor play areas, separate infant and toddler sleeping rooms, educational activities and therapies. Decors are bright, friendly and resemble typical daycare settings. Nursing stations and treatment rooms are the only obvious indications

of a controlled, clinical environment.

Most centers accept children with a developmental age of less than six years who are considered medically complex, require skilled nursing interventions and are technology dependent. Diagnoses may include failure to thrive, multiple congenital anomalies, respiratory conditions, cancer, cardiac disease or other conditions.

Some centers offer care to children with less complicated medical conditions such as those requiring only cardiac-respiratory monitoring. Additionally, "typical" children may also be integrated into the program to promote peer relationships and acceptance.

Medical models

These centers are medical models, meaning they are staffed by nurses specializing in pediatric and neonatal care; physical, occupational and speech therapists; child-life specialists and medical social workers. Some centers also include respiratory therapists.

An average 3:1 child-to-staff ratio is typical, depending on a particular child's needs. Many high-tech therapies can be provided on-site with



some centers housing their own pharmacy. Medical equipment designed for home and alternate site use can also be accommodated. Developmental therapies-including physical, occupational and speech therapies—can be provided in groupbased, day-to-day activities and individualized sessions.

Centers are licensed by state daycare licensing authorities or PPEC (Physician Prescribed Extended Care, licensing agencies recognized in some states, including Florida and Delaware). Most centers are located in community-based settings, making transportation more convenient. Some centers can arrange transportation to and from home or school.

Self-confidence and acceptance

Early childhood education and/or child-life services are all a part of caring for the child. These centers promote self-confidence and acceptance, and prepare children for a smoother transition into the community school



Photo courtesy Child Health Systems, Westwood, MA.

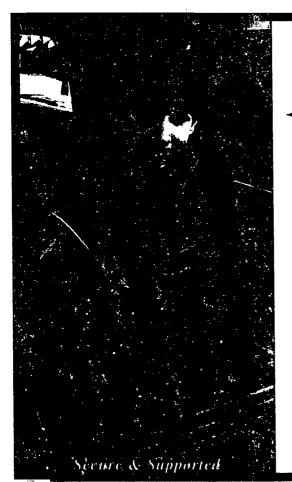
system by emphasizing social, emotional and intellectual development as well as normal growth and developmental tasks such as toilet training, feeding and motor skills.

Cost-effective care

As managed care gains momentum, hospital stays are shortened and more care is shifted to families and community-based providers. The need for more cost-effective alternate-care settings is growing. A child can attend one of these centers at a cost that is about 25-30 percent less than traditional home-care nursing (which already is a fraction of the cost of hospitalization). This does not include the savings from decreased rehospitalizations, earlier hospital discharges and the fact that children who are medically complex progress more rapidly in a stimulating, clinically-structured envi-

For parents of children who are considered medically fragile, the struggle to find special daycare services is extremely difficult. This exciting new model gives families and children not only a sense of control, but a sense of normalization.

Wanda Monical has worked in the health care field for 15 years and is the founder of Home Care Solutions, an Atlanta-based consulting firm specializing in new business development and alternate site delivery centers.



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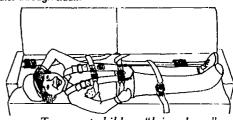
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A R L

Making the Transition to Group Care

by Mary M. Donegan, Dale B. Fink, Susan A. Fowler and Michael W. Wischnowski

n important milestone in any young child's life is the start of attendance in a group care setting. In earlier generations, this step was usually associated with the beginning of first grade or kindergarten. In North America in the 1990s, this is no longer the case; most children now attend some kind of half- or full-day daycare prior to kindergarten.

Families as well as staff working in early childhood and early intervention programs have come to recognize the entrance into such programs as a period of adjustment for many

young children and their parents. This article presents strategies that may ease adjustment problems and decrease the amount of time required for a young child to make a successful adjustment to the new setting:

- Begin early: Advance planning allows parents enough time to prepare the child as well as themselves. This also assures there will be adequate time to search for a setting that is the least restrictive and most appropriate.
- Talk about the new setting in positive ways: Equating transition with getting to be a "big boy" or "big

girl" and showing pride in the child's increasing maturity and independence helps the child focus on the positive aspects of this change. Sometimes referred to as positive forecasting, this helps the child begin to anticipate what to expect in the near future. Another way of presenting the new setting in a positive light is to spend time with the child looking at a copy of a brochure from the new program, particularly if it contains photographs of the building, the classrooms, smiling children and affectionate teachers. Some programs have produced

Joey Gave Us the Tools

Daycare workers who are committed to inclusion have plenty of experience facing tough challenges. We learn sign language. We adapt physical settings to accommodate wheelchairs. We take on medical responsibilities not typically considered part of daycare work.

But Michael, a child with autism/PDD (pervasive developmental disorder), brought a whole new set of challenges to the University of Winnipeg Students' Association Daycare.

Compared to Michael, adapting our program for a child with cerebral palsy or Down syndrome had been easy. Michael made limited eye contact, fixated on toys or other objects for hours and had difficulty coping with even small changes in his environment. Just moving a table could cause him to scream and flap his arms ε d withdraw for days.

We wanted to include Michael but knew we needed some help. Fortunately, we found Joey Kheisz, a psychiatric nurse with Preschool Consultation, part of the Manitoba-based Autism Services program. Joey gave us the tools to help Michael learn to anticipate, make choices and participate in activities. Stressing the importance of structure, routine and repetition, Joey recommended specific strategies:

- Have a written script—literally, a plan for every period in Michael's day.
- 2. Use a "routine minder"—a photographic guide to Michael's daily schedule.
- 3. Carefully prepare Michael for each transition or change.
- 4. Integrate Michael into highly predictable activities one at a time and let him learn each one well.
- 5. Slowly bring other children into the routines of Michael's day.
- 6. Build on Michael's comfortable activities to broaden his horizons.

I began by working one-to-one with Michael in a quiet area. Every morning, Michael's mother reminded him he would see me and showed him my picture. Then, in the privacy of the quiet area, using the same words and pictures every day, his mom and I would prepare him for her leaving.

Soon, we were able to take the first steps to include Michael with other children. We started with morning Sing-Song time. Since we wanted Michael to be part of Sing-Song, we had to plan songs in advance. Now, we always start the day with the same "Good Morning" song, followed by the same alphabet song and then a song we call "Michael, Michael, Woo, Michael." After three songs, Michael leaves and has a snack. We discovered the other children also enjoy the predictability of the first three songs.

Our next goal was to bring another child into Michael's private day. After snack, Michael and I always worked together on a puzzle while other children played nearby. One child, who was interested in the activity and seemed to have skills that would help Michael, was invited to join. I helped Michael rehearse for this child's inclusion by telling him the girl's name and showing him her picture. After several days of her participation, Michael showed interest in her when she appeared. Now, other children have also been recruited to join Michael's activities. And by carefully adding components of the unfamiliar to the familiar, Michael's participation in regular daycare activities has increased.

Difficulties remain. Events sometimes counter attempts to make Michael's day predictable. The fire alarm may go off unexpectedly or another child may be absent. But by using scripting, rehearsal and routine, Michael has been reached and is gaining a repertoire for social interaction.

—Merilyn Renaud

Merilyn Renaud is a special needs facilitator in Winnipeg, Manitoba, Canada.



videos that can be shared.

Helping the child shop for a new book bag, backpack or lunch box—which will not be used until the first day of the new program—can present another opportunity for positive forecasting.

• Encourage the child to ask questions and express fears: Be accepting of a child's worries, rather than dismissing or making light of these feelings. For example, if a child says he won't go to the new program unless his brother or sister also goes, an adult can say something like, "We will miss you, too. We will be waiting for you when school is over."

Use dramatic play and storybooks to anticipate upcoming changes. Pretend play can help children deal with fears as they pretend to take a bus or find their cubby at the new school. Parents and children can share storybooks in which a child starts school or goes to daycare for the first time. Such books can help children understand that it is all right to feel sad and afraid, but also that things usually work out just fine.

• Engage the child in group experiences: Children who have had no previous large-group experiences, will benefit from exposure to groups of children in new environments. Activities such as story hour at the local library can provide good large-group experiences.

It may also be possible to arrange play dates in advance with one or two of the other children who will be attending the program. Knowing at least one other child's name and face before entering the new environment will help the child look forward to the experience.

Arrange visits to meet teachers and to observe or join in classroom and playground activities. Plan the first visit for a time when fewer children will be there so the child can explore the classroom and become familiar with staff.

Help the child identify similarities and differences between current surroundings and the new program. For example, an adult may point out that the new school has a slide just like the one at the park. If possible, videotape activities and be sure to include

Sharing Confidential Information?

Sharing information among the programs that serve a child with special needs and forwarding records to new service providers are key ingredients to ensuring a timely transition and
easing a child's adjustment. Providing new program staff with up-to-date information about a
child's abilities and disabilities can educate new caregivers, prevent unnecessary duplication
of services and ensure that children will be able to get the most from a new program. However, parents and staff often have concerns regarding how much, when and what type of
information should be shared. This is especially true when a child, with special needs is entering a program where most of the other children are perceived as "typical."

Families of children with disabilities may fear that sharing their child's diagnosts or other confidential information may result in lower expectations on the part of the staff Some parents fear that the child will be stigmatized. Staff may have their own concerns about telancing parents' and children's rights to privacy with the need to share information that could ease a child's adjustment.

Some parents use a wait-and-see approach—they provide information only as events make the information relevant or helpful. While this approach allows parents some control, it may delay the sharing of important information. Some programs expect parents to sign release forms before transition planning occurs. These forms allow program directors to decide when and if specific staff members need access to the information.

This is not an easy issue. How have you dealt with these requests? We'd appreciate hearing about your experiences and perspectives. Write to us at FACTS/LRE, University of Illinois at Urbana-Champaign, 61 Children's Research Center, 51 Gerty Dr., Champaign, it 61820.

- Mary M. Donegan and Dale Fink

close-ups of staff members. Show the video at home.

Whenever possible, give your child the opportunity to make some real choices. For example, if the transition involves leaving another program, let the child choose a special treat to bring for the staff and the other children in that program.

In preparing for the new program, let the child choose a toy or other object that can travel back and forth from home with him and sit in his cubby during the school day. A favorite toy or family photograph is familiar and comforting to the child; it also gives the child something to talk about with his new caregivers.

• Teach useful skills and routines: Children can benefit from opportunities to learn and practice independent skills that are considered important in the new environment. Observations of the classroom routine and discussions with staff members can help parents and therapists determine skills the child will need to function as independently as possible.

Practice selected classroom "survival skills" throughout the year or a few months before the transition. For

example, putting toys away after playing with them can be taught all year long. However, skills more specific to the new program—for example, sitting on a carpet square for circle time—may be introduced shortly before the transition.

It is very helpful to find out in advance how daily routines such as bathroom, nap time and transitions between activities are handled. For example:

- Are children taken to the bathroom as a group? Are they expected to tell the teacher on their own when they need to go?
- If there is a nap time, is the child expected to recognize his own blanket or find her own name on a cot? Is the child expected to carry a cot to a designated spot?
- How does the teacher indicate that it is time to come inside when children have been out on the playground? Do they form a line? Are the same cues used for transitions before or after other activities?

Before the child enters the program, it is important to inform the staff about the child's progress in mastering skills needed to function independently. This is especially



important if the new environment is a regular early childhood setting in which the child will be one of only a few children with special needs. To ensure continuity and success for the child, it will be important to arrange for program staff to support and continue instructing the child in these skills.

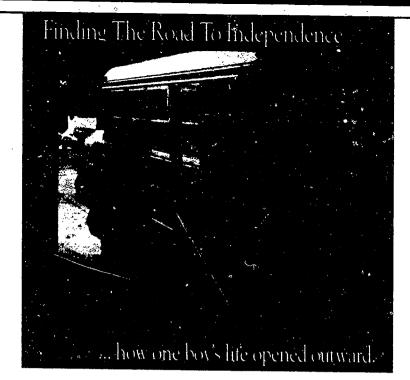
• Communicate and share information in advance: Parents or therapists may be able to demonstrate positioning, handling or feeding techniques. They may also be able to inform the child's new teachers about ways to prevent or deal effectively with difficult behaviors.

It is also useful to discuss rules regarding privacy and confidentiality (see sidebar on page 30). How much information should be shared with staff members? How much information should be given to parents of other children?

Working together, parents, members of the child's team and staff of the new program ca. assist children and families in developing a sense of comfort and trust in the new setting.

This article was adapted from a publication of FACTS/LRE (Family and Child Transitions into Least Restrictive Environments), a federallyfunded outreach project of the Office of Special Education Programs, US Department of Education. Susan A. Fowler, Ph.D. is project director, Dale B. Fink is project coordinator, and Mary M. Donegan and Michael W. Wischnowski are associates. Fink, Donegan and Wischnowski are doctorul candidates in the Department of Special Education, University of Illinois at Urbana-Champaign; Fowler is department head.

The booklet from which this article was adapted, Entering a New Preschool: How Service Providers and Families Can Ease the Transitions of Children Turning Three Who Have Special Needs, can be ordered from IRHD Publications, 61 Children's Research Center, 51 Gerty Dr., Champaign, IL 61802. The cost is \$2.50; make checks out to "University of Illinois." You may also write for more information about FACTS/LRE and an order form listing cll project publications.



Brandon was once filled with rage. He pinched, kicked, bit, and scratched the people he loved, often hurting himself in the process.

His anger was understandable. Blind since birth, having cerebral palsy, and other developmental disabilities, Brandon had great difficulty performing even the simplest tasks. He wanted independence, but could barely communicate even his most basic needs.

After making limited progress at a school for the visually impaired, Brandon came to Heartspring. An interdisciplinary team of Heartspring specialists explored his specific challenges and began the process of helping Brandon to learn more acceptable ways of expressing his wants and needs.

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Before long, a wonderful young man began to develop. Embracing the new possibilities in his life, Brandon learned new orientation and mobility skills so he can go by himself from his classroom to lunch everyday and many other places at home and on campus. He now takes rhe school bus home on Fridays to spend time with his family. Down the road, Brandon will return home and to his public school. We want to help him with that journey.

If you know a child with multiple disabilities who needs help finding the road to independence, call Heartspring today. Together we can make a difference.



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Readers Talk About: CHILD CARE

A few months ago, we asked readers to tell us about their experiences finding child care for young children with disabilities. Here are some of the stories they shared...

"Friends, Mommy. Friends"

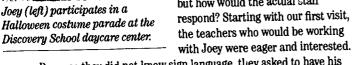
Our third child, Joey, who has Down syndrome, began daycare at a center for children with disabilities when he was 10 weeks old. When Joey was almost two, a staff member suggested that he move to a regular daycare center. I thought any center would beg to accept my son in order to enrich the lives of the other children. Ten phone calls later, I realized it wasn't that simple. Most were not interested in "the challenge." Others promised to call back, but never did.

Finally, I called the area director of the Discovery Schools.

I told him a little about Joey-he signed more than he spoke, was physically awkward and had not yet mastered the art of feeding himself with a spoon.

I waited for the inevitable silence. but there was none. Instead, I was assured that the chain had a policy of non-discrimination and would be happy to accept Joey.

We had cleared the first hurdle, but how would the actual staff respond? Starting with our first visit, the teachers who would be working



Because they did not know sign language, they asked to have his speech therapist teach them the signs he used.

As Joey moved from the infant to the toddler class, we watched him bloom. Eating lunch with other children did more to encourage him to feed himself than everything we'd tried at home. The teachers labored with Joey over his attempts to paint and hold scissors and facilitated his interaction with the other children.

Last September, at age four, Joey advanced to the preschool class. Although potty-training was a prerequisite for this class-a milestone Joey had not yet achieved—the staff recognized his need

to be with his peers.

A few weeks ago I arrived at the center to pick Joey up. The children were outside on the playground, so I went in to collect Joey's things. In his cubby, under the day's artwork, lay a small, white envelope. Heart pounding, I opened it to find an invitation to a classmate's birthday party.

Outside, I found Joey climbing the monkey bars with two other boys. He greeted me, then motioned enthusiastically to his companions. "Friends, Mommy. Friends," he said happily. And I thanked God for Discovery School.

-Teresa L. Nelson Mechanicsburg, Pennsylvania



lthough my husband and I were uncomfortable placing our Afour-year-old son with Lennox-Gastaut syndrome, into daycare, we had no choice. I had to work and my mother-who had been caring for Craig-had passed away.

We knew it wouldn't be easy finding an appropriate program. We finally decided on a center where he would be the only child with special needs. I chose this program because it was very small.

Within a month, I had become quite unhappy with many aspects of the program. The staff complained about Craig messing his pants everyday—it turned out nobody was remembering to put him on the toilet. The staff made no efforts to include Craig in activities with the other children; he spent most of the day aimlessly walking around with his lunch box.

I called a meeting with the director. I explained that Craig had autistic characteristics and tended to fixate on objects. I suggested they put the lunch box out of his reach and offer him the chance to participate in more beneficial activities.

I hoped this meeting would make things better, but things became worse. I walked into the center one day and, to my horror, found Craig restrained in a chair with a belt. A staff member told me she was "trying to teach him something."

I called another meeting and demanded they stop using restraints with my son. I told them Craig would sit still if he was involved in an interesting activity.

But the staff continued to restrain

Craig. I called his case manager at the state mental retardation board. We met with the center director and her immediate supe-

rior. The center director and her boss kept referring to "Craig and the kids."

I explained that Craig is one of the kids. "You wouldn't strap a typical child to a chair,would you?" I asked.

I decided to go straight to the top. I called another meeting—this time with the program's regional director. I explained my reasons for choosing the program and told her how badly I wanted it to work. I reminded her that Craig had a legal right to participate.

Eventually, local director was fired; since then, the situation has improved. And to make sure it continues to be a good environment for Craig, his case manager makes frequent surprise visits.



Craig interacts with a friend at daycare.

Readers talk vbout:

We invite you to the discussion in future issues of Exceptional Parent. In upcoming months, readers will be talking about:

- facilitated communication (May; deadline March 15, 1995)
- talking with a child about his or her disability (June; deadline April 1, 1995)
- helping a child make fnends (July; deadline May 1, 1995)
- experiences with genetic counseling (August; deadline June 1, 1995)
- educational options---special schools or inclusion (September; deadline July 1,

Write to: Readers Talk, Exceptional Parent, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

- Colleen Nowotka Toledo, Ohio



Wet, But Happy

My five-year-old son, Ben, has multiple, severe disabilities as the result of a rare genetic disorder. He is very social and loves to be with other children. This year, for the first time, Ben is

attending a regular daycare program—a districtoperated after-school program for school-age
children; Ben is the only child with a disability. I
chose this program because it is the one his
brother attends and because it is my intention
that Ben be fully included for kindergarten next
year at the neighborhood so col where this program is housed.

The staff expressed some concern, but no actual resistance to including Ben. After two months, everyone seems pleasantly surprised at how easy the transition has been and how well Ben fits into the program. The staff loves him; he loves the program; and I am thrilled to see the other children treating him like just another kid.

The one huge wart on this otherwise pretty picture has been the district administrator to whom the program director reports. She has instructed the staff that they are not to assist Ben with toileting. Ben still wears diapers, stays dry for long periods of time, and almost never has a bowel movement in the afternoon, so this has not yet become a practical problem. It is inevitable, however, that Ben will someday

have a bowel movement while at daycare. The administrator's solution is that a staff member will call me at work and I will stop whatever I am doing and come to change his diaper.

An even greater problem is that Ben is in the process of becoming toilet trained. He is not physically able to pull down his pants

or to move from his wheelchair onto the toilet—for him, toilet training means learning to ask to use the toilet. We are pleased that he has started to communicate his need to use the bathroom. However, if and when he communicates that need at daycare, the staff have been instructed to tell him, "Sorry kid, you're on your own." My efforts to tell the administrator how devastating this could be to Ben's selfesteem has been met only with sympathy for my "situation."

Ben's next IEP meeting is coming up and I intend to include his participation in this program as part of his IEP. At that point, if the district administrator still refuses to accommodate his toileting needs, I intend to file a complaint with the Office of Civil Rights.

In the meantime, Ben is happy—albeit wet. The staff is doing a great job despite the constraints placed on them by their administration, and the other kids in the program are learning that kids with disabilities are more like them than different.

—Marcia C. Todhunter San Francisco, California



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Child Care and the ADA

by Rita D. Siegle

Act (ADA) is a powerful statement of civil rights for persons with disabilities. Title III of the ADA prohibits discrimination on the basis of a disability for many private businesses; this explicitly includes daycare centers. All child care programs, including family daycare homes, must comply with the ADA.

Defining discrimination

The ADA defines a person with a disability as someone:

- with a physical or mental impairment that substantially limits one or more of the major "life activities" (caring for oneself, performing manual tasks, walking, seeing, speaking, breathing, learning or working),
- with a history of such an impairment (for example, a child who had cancer but is now in remission), or
- regarded as having such an impairment (for example, a child with a cranio-facial condition who "looks different").

The ADA prohibits child care programs from discriminating against any child in one of the above categories. It also prohibits discrimination against a child who has a family member with a disability.

For more information...

These resources provide general information about the ADA. They can also answer questions and provide guidance with regard to specific situations or concerns:

Two ADA Information Line
(600) 514-0301 (voice).
(600) 514-0383 (TTY)
Calers may access recorded information and order publications 24 hours a day. To speek with an ADA exercises from the US Department of Justice, call Monday Friday, 10 a.m.—6 p.m. EST.

Child Cere Inter Conter

(415) 495-496 (voice)

Relephone Viole heurs are Tuesdays or Thursdays, ncon 3 p.m. PST, us write to Child Care-Law Cereer 22 Second St., 5th FL, Sen Franzisco, CA 9 105.

"Reasonable modifications"

The ADA requires child care providers to make "reasonable modifications" for equal access to program participation. These may include: revision of policies and procedures, removal of physical barriers, provision of adaptive equipment, curriculum adaptations and changes in staffing patterns and training.

Some exceptions

A provider is allowed to exclude a child with a disability if he poses a "direct threat" to himself or others, which cannot be overcome by reasonable modifications. But before a child can be excluded for this reason, the provider must document efforts made to include the child.

The provider may also exclude a child if accommodating the child:

- requires changes that fundamentally alter the nature of the program, and there are no reasonable alternatives.
- requires provision of equipment or services that would be an "undue burden" (significant difficulty or expense) on the provider, and there are no alternative accommodations.
- requires architectural changes that are not "readily achievable" (easily accomplished without significant difficulty or expense), and there are no readily achievable alternatives.

"Undue burden" and "readily achievable" can have different meanings depending on a program's resources. For example, a large chain of child care programs that typically provides transportation services may be able to buy a wheelchair lift for a van; for a family daycare home, this would create an "undue burden."

Denying care to a child under an allowable exception does not mean a provider may exclude others with the same disability. Each child's needs must be assessed individually.

Grey Areas

• Cost: Even if accommodating a child results in additional expenses,



Ian Keith (in stander) enjoys art class at Rainbow Station Child Development Center in Richmond, Virginia. Ian has cerebral palsy and is hard of hearing.

the facility may not charge his or her parents extra fees. However, these costs may be passed on to all participants in the program.

- Disclosure: Parents are not required to disclose a child's special needs. But if not disclosed, a provider cannot be expected to accommodate those needs.
- Religious entities: The ADA exempts programs operated by religious organizations unless they receive any type of federal funding.

Rita D. Siegle, M.Ed., works at Dependent Care Management Group, a consulting company in San Antonio, Texas, where she supervises a child and elder care resource and referral program.

with permission from CHILD CARE FOR ALL CHILDREN: A REFERRAL COUNSELOR'S GUIDE TO INCLUSIVE CARE. (See CHILD CARE RESOURCES on page 35.) Funding for the book was provided by the Texas Employment Commission Work and Family Clearinghouse through a Dependent Care Block Grant. The book was written by Rita with support from Nancy Hard, president of Dependent Care Management Group and project manager of the Inclusive Child Care Project of Texas.

Child Care Resources

ADA-RELATED PUBLICATIONS

The ADA and Child Care Providers

Answers questions providers may have about ADA requirements. Free.

 Action for Better Child Care, United Cerebral Palsy of Greater Atlanta, 1776 Peachtree St NW, Ste 522 S, Atlanta, GA 30309, (404) 892-2252

All Kids Count

For caregivers and parents. Lists resources. 89 pp. \$12.50.

 The Arc, PO Box 1047, Arlington, TX 76004-1047

Caring for Children with Special Needs: The ADA and Child Care For child care providers. Addresses legal

concerns. 40 pp, \$10. Child Care and the ADA: Highlights for Parents

For parents of children without disabilities, 16 pp. \$5.

Child Care and the ADA: Highlights for Parents of Children with Disabilities

Overview of ADA requirements; actions to take if a program does not comply with ADA. 19 pp, \$5.

The Child Care Law Center, 22 Second St, 5th FI, San Francisco, CA 94105. (415) 495-5498

Understanding the ADA: Information for Early Childhood Programs
For child care providers. Free.

 National Association for the Education of Young Children, Box ADA, 1509 16th St NW, Washington, DC 20036

GENERAL PUBLICATIONS

Caring for Children with HIV or AIDS in Child Care

For child care providers. Legal issues, practical concerns. 36 pp, \$10.

 The Child Care Law Center, 22 Second St, 5th FI, San Francisco, CA 94105, (415) 495-5498

Child Care for All Children: A Referral Counselor's Guide to Inclusive Care

Comprehensive guide for referral counselors. Shows how parents, providers and counselors can work together to make inclusion work. 80 pp, \$20.

 Dependent Care Management Group, 130 Lewis St, San Antonio, TX 78212, (210) 225-0276

Child Care for Children with Special Needs

Helps parents assess how well child care providers address children's needs. Outlines key questions to ask.

Free to MN parents; \$2 for others.

PACER, 4826 Chicago Ave S, Minneapolis, MN 55417, (612) 827-2966

A Great Place to Be Me: Selecting a Child Care Program When Your Child Has a Disability

Information guide for parents. 20 pp; \$7.50.

• Child Care Plus, Rural Institute on Disabilities, The University of Montana, 52 N Corbin Hall, Missoula, MT 59812, (800) 235-4122

Including All of Us—An Early Childhood Curriculum About Disability Guide to developing a classroom that is nonsexist, multicultural and accessible.

Pub. 1984, 144 pp, **\$10.95.**• Gryphon House, 3706 Otis St, PO Box 275. Mt Painier. MD 20712

Including Children with Special Needs in Early Childhood Programs Research monograph. Practical tips. 230 pp. \$8.

A Place For Me: Including Children with Special Needs In Early Care and Education Settings

General guide fo: providers. Addresses questions typically-developing children may have, 85 pp; \$4.50.

 National Association for the Education of Young Children, 1509 16th St NW, Washington, DC 20036

In the Mainstream—From the Beginning?

Final report of a statewide (NY) study of child care for children with disabilities. Includes descriptions of programs and quotes from parents. **Free.**

 New York State Developmental Disabilities Pranning Council, 155 Washington Ave, 2nd Fl, Albany, NY 12210, (600) 395-3372

Integrating Children with Special Needs Into Pre-School Settings: A Resource Handbook

Extensive bibliography of resources. 87 pp. \$5.

 Child Care Careers Institute Information Clearinghouse, 71 Summer St, 3rd FI, Boston, MA 02110, (617) 338-6420

MITCH—Model of Interdisciplinary
Training for Children with Hendicaps
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Series of 13 easy-to-read manuals covering all aspects of caring for children with disabilities in inclusive settings. 80–130 pp, \$5–7 each.

 MITCH, c/o FDLRS/South, 5555 SW
 93rd Ave, Miami, FL 33615, (305) 274-3501

More Alike Than Different: Including Children with Special Needs in School-Age Settings

Curriculum for a series of 12 workshops to train child care providers. Includes instructions and handouts. **Free.**

 New Jersey Department of Human Services, 222 S Warren St, CN 700, Trenton, NJ 08625, (609) 984-0879

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Questions and Answers: Choosing Child Care for Children with Special Needs

Answers parents' questions about choosing child care for children with disabilities. Lists resources. 16 pp, \$3.

Questions and Answers: Working with Parents of Children with Special Needs

For child care providers. Lists resources for more information. 32 pp, \$3.

Community Coordinated Child Care, 225 Long Ave, Bldg 14, Hillside, NJ 07205

The SpeciaLink Book: On the Road to Mainstream Child Care

Reference guide to inclusive child care in Canada and a record of the SpeciaLink Symposium. 178 pp. \$18 (US or Can.).

SpeciaLink, 186 Prince St, Sydney, NS Canada B1P 5K5, (902) 562-1662

VIDEOTAPES

ABC's of Inclusive Child Care

Shows a variety of child care settings in which children with disabilities have been included: 14 min. Free.

 Texas Council for Developmental Disabilities, Attn: Lucy Walker, 4900 N Lamar Blvd, Austin, TX 78751-2399 (512) 483-4093

Just a Kid Like Me

Demonstrates three environments—a family daycare home, a child care center and a school-age program—integrating children with disabilities. 28 min., \$25 purchase; \$15 rental.

 Child Care and Family Services, 155 N Occidental Blvd, Los Angeles, CA 90026, (213) 427-2700

The Mainstream is the Right Stream Shows methods for including children

Shows methods for including children with disabilities. One segment gives an overview; four segments show children with blindness, a medically-fiagile condition, cerebral palsy and autism being included. Available in English or French. 60 min., \$40 (US or Can.).

• Special.ink, 186 Prince St, Sydney, NS Canada B1P 5K5, (902) 562-1662

Same Time, Same Place

Shows children with different types of disabilities in three different child care settings. 15 mln., \$18.

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Specialink

Promoting a vision of inclusive child care in Ganada

Special ink, Canada's National Child Care Mainstream Network, is a non-profit organization that grew out of 15 years of front-line work in an inclusive child care center that became a national model. The organization aims to increase the quantity and quality of inclusive child care in Canada and to bring children who are currently excluded into the mainstream. Special ink does research on successful, inclusive child care programs, develops resources for child care workers and parents and promotes changes in government policy.

Special ink works toward full inclusion in a milieu very different than the United States. In the U.S., laws mandate a "free, appropriate, public education" for children with disabilities (the Individuals with Disabilities Education Act) and outlaw discrimination on the basis of disability (the Americans with Disabilities Act), in Canada, however, the inclusion of children with disabilities in child care and educational settings is strictly voluntary. Nonetheless, hundreds of Canadian child care programs are finding ways to include all children.

Based on the best elements shared by these programs, SpeciaLink has developed a vision of what Canadian child care will look like when it really includes all children. That vision presupposes a high-quality, affordable, accessible, comprehensive national child care system-it doesn't make sense to include a child with special needs in a poor-quality program; and it doesn't make sense to offer inclusive child care if the price, hours or location of that care make it inaccessible to families who need it. This vision implies many assumptions about funding, training, consultation, knowledge and commitment.

To promote the goal of inclusive child care, Special ink creates publications and videos (see "Child Care Resources," this page), and offers conferences and presentations spotlighting innovative, inclusive programs. U.S. readers who share the Special ink vision are invited to become "International members" of the network to receive the newslatter and other mailings (US \$15/year). For more information, contact Special ink, 186 Prince St., Sydney, NS Canada B1P 5K5, (902) 562-1662.

---Sharon Hope Invin, Director



ROLE MODELS

Irving Kenneth Zola

January 24, 1935 - December 1, 1994

Rereading Irv Zola's writings in EXCEPTIONAL PARENT, I again realized the magnitude of his loss—just as I had when sharing his memorial service at Brandeis University in mid-December with hundreds of others whose lives he had touched.

Below, we reprint an excerpt from an article by Irv, "A Story Difficult to Hear and Tell," originally published in Exceptional Parent in January 1979, a year before he joined our Editorial Advisory Board. Since this piece discusses serious topics, I want readers who did not have the privilege of knowing Irving Zola to know that he was a joyful person with a wonderful sense of humor. He was a loving husband, father and grandfather and a brilliant scholar—truly a role model.

Exactly 10 years ago—February 1985—we reported the death of Burton Blatt, another long-time member of our Editorial Advisory Board. Burt was another great leader, tireless advocate for human rights and personal friend. Knowing how Burt's influence has lived on helps me mourn now for Irv Zola.—S.D.K.

am by professional training both a social observer and a psychological counselor. Yet, for more than two decades, I have succeeded in hiding a piece of myself from my own view. Given the obviousness of my physical disability, this has taken some doing.

Between the ages of 15 and 20, I suffered two major traumas—first polio and then, four years later, an automobile accident. Each resulted in a year's confinement and each was severely debilitating...

As a result of these "medical incidents," I wear a long leg brace on my right leg, a steel-reinforced back sup-

port and I use a cane. My children, when very young, described me as "walking funny." To the rest of the world, I limped. To me, all of it was just something that got in the way, another difficulty to be overcome. For 20 years, I devoted more psychological and physical energy to this task than I have ever realized. Overcoming is not the same as integrating. This is one of the bittersweet lessons...

For a long time, myself and many other "successful mainstream adapters" have not numbered among our close friends and acquaintances any handicapped people—a remarkable "alienation" from our disability.

Achievement syndrome

Written accounts about "successful" handicapped persons, as well as every "success" that I have met (including myself), almost always make this statement: "I never

think of myself as handicapped." Yet the degree to which this is true may have made it virtually impossible to tell anyone what it is like to be disabled in a world of normal. In a real sense, we do not knew. Thus, what the public learns from our example is decidedly limited...

So, too, with the other folk-heroes of disease—not the little people, not the millions, but the few who are so successful that they "pass." They are all so good that no one knows or has to be aware of their "handicap," and therein lies part of their glory...

I have come to realize how distorted and unrepresentative such "success" stories really are. The wish to disbelieve this is great. And we all—able-bodied and disabled—continually seduce ourselves into thinking otherwise. The media is particularly helpful in this task and a specific example sticks painfully in my mind.

I am a sports fan and, as such, an avid watcher of major events. The 1976 Olympics found me glued to my TV set and I was pleasantly surprised by a documentary which

related to me quite personally... It told how six athletes had overcome some problem and gone on to win Olympic gold medals.

One story really grabbed me. It was about Wilma Rudolph, a woman who'd had polio as a child... Through exercise and hard work, she started to walk slowly

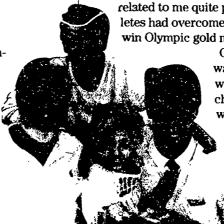
with crutches. Then she abandoned them to begin to

run. And there in the final frames she was springing down the track straining every muscle. With tears streaming down my face, I shouted, "Go on, Wilma! Do it!"

And when she did, I collapsed, too—exhausted and exhilarated

But 90 minutes later I was furious. A basic message of the film had sunk in. In each case, the person overcame. But overcame what? Wilma's polio was not my polio! All my hard work could *never* have allowed me to win a running race, let alone compete in one.

My point is that in almost all the success stories that get to the public, there is a dual message. The first one is very important—just because we have polio, cancer or multiple sclerosis, or have limited use of our eyes, ears, mouth and limbs, our lives are not over. We can still learn, be happy, be lovers, spouses, parents—even achieve great deeds. It is the second message which I have recently begun to abhor. It states that if a Wilma Rudolph could overcome her handicap, so could and should all people



Irv Zola (left) with children Amanda(standing), Kyra (center) and Warren



with disabilities. If we fail, it is our problem, our personality, our weakness...

Keeping a distance from the disability

...Achievement syndrome blinds not only the general public, but also the achievers. We are paid the greatest of compliments when someone tells us, "You know, I never think of you as handicapped." And we gladly accept it. We are asked, "How did you make it against such great odds?" And we answer the question. Yet, in both the being and the answering, we further distance ourselves from the

problems of having a handicap. In a sense, they become both emotionally and cognitively inaccessible...

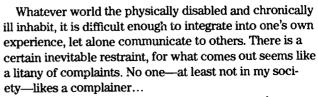
Let me illustrate with a personal example. I do a great deal of long-distance traveling and often find my flight leaving from a distant gate... Adjusting to this, I had ordinarily allowed myself an extra 20–30 minutes to get there. I regarded this as a minor inconvenience. And if, perchance, you had asked me then if I experienced any undue tiredness or avoidable soreness, I would have firmly and honestly answered. "No."

In 1977, piqued that I should continue to inconvenience myself, I began to use a wheelchair for all such excursions I thought the only surprise I would encounter would be the dubious glances of other passengers when after reaching my destination, I would rise unassisted and walk briskly away... But much more disconcerting, was that I now arrived significantly more energetic, more comfortable, freer from cramps and leg sores than in my previous decades of traveling. The conclusion was inevitable. I had always been tired, uncomfortable, cramped and sore after a long journey. But with no standard of comparison, I did not "experience" the tiredness and discomfort...

The very process of successful adaptation not only involves divesting ourselves of any identification with being handicapped, but also denying the uncomfortable features of that life. The denial of discomfort has made many success stories possible. But this process has a cost. One may accept and forget too much.

No Special World

There is no special world of the disabled person, and herein lies another major problem... Most minority groups grow up in some special subculture, and thus form a series of norms and expectations; the physically disabled are not similarly prepared. Born for the most part into normal families, we are socialized into that world... The very vocabulary we use to describe ourselves is borrowed from that society. We are deformed, diseased, disabled, disordered, abnormal, and most telling of all, invalid. Almost all of us share, deep within ourselves, the hoped-for miracle to reverse the process—a new drug or operation which will return us to a life of validity...



Chairs without arms to push myself up from; showers and toilets without handrails to maintain my balance; staircases without banisters to help hoist myself; buildings without ramps, making ascent exhausting, if not dangerous; every curbstone a precipice. With such trivia is my

life plagued...



With whom can I share the satisfaction that I did not trip, that my brace did not break, that I did not have difficulty with toilet facilities, that I made it by myself? When hospitalized with polio, I was tearful when I first defecated without the aid of a laxative. Even more exciting, after months of impotence, was my first erection.

My first steps in walking I could share, but not excessively, with my

parents and friends. My bowel movements were at least acknowledged by the medical and nursing staff.

However, my sexual issues were kept achingly to myself. Even amongst my fellow residents, socialized as they were into the world of the normal, there was only limited access to any sharing... I gradually learned that no one, including myself, really wants to hear the mundane details of being sick or handicapped, neither the triumphs nor the hardships.

I am sure the specific details and hardships of having a handicap or chronic disease vary from person to person—but not the core problem. The story is inevitably difficult to both hear and tell... As such, the only defense, the only way to live, is to deny it. But then it becomes socially invisible to all. We—both those with physical disabilities and those without—are sadly left deprived of the very knowledge, skill, resources and motivation necessary to promote change.

IRVING KENNETH ZOLA SCHOLARSHIP FUND

tual architect of the field, Irv played a unique role in weaving together a community of scholars. He was personally involved in nurturing the work and lives of thousands of colleagues, students and advocates. We will miss his thoughtfulness and energy, his warmth and humor, and his courage and caring. Irv embodied what so many of us seek—the combination of intellectual insight and a life committed to humane values and social justice.

We have created the Irving Kenneth Zola Scholarship Fund to support the professional development of graduate students in disability studies.

---Richard K. Scotch, President, Society for Disability Studies

Contributions may be made to "Irving Kenneth Zola Memorial Fund" and sent to Fred Hafferty, Treasurer, Society for Disability Studies, 3109 E. Superior St., Duluth, MN 55812.



182

Irv (right) with daughter Kyra and

grandson "Lucky."

Proper Seating and Positioning

to participate in the everyday activities of life while using their maximum abilities, children with disabilities must be seated in a comfortable position. Proper seating and positioning allows children to use their bodies and minds to the best of their abilities without worrying about balancing and personal safety.

"A seating system is the center of all other activities," says Elaine Trefler, M.Ed., OTR, an assistant professor in the School of Health and Rehabilitation Sciences at the University of Pittsburgh and expert on seating and positioning. "If a child is well seated and comfortable, the child will be able to participate at his or her optimum."

When to start

Although premature babies have been fitted for positioning equipment, parents are likely to begin the process when their child is about six months old because of the increased need for and use of car seats, highchairs and strollers. This is also about the time when a diagnosis is clear and the child may start to fall behind on motor

The most important step for ensuring a child is fitted with a proper seating and positioning system is a thorough evaluation and prescription by a qualified team. The team should include physical or occupational ther- Products, Northbrook, IL. apists, a physician specializing in rehabilitation medicine or orthopedics, a rehabilitation technology supplier and parents.

skill development.

Other members of the team may include school therapists and classroom teachers if the child is in school, and a rehabilitation engineer if the child has severe disabilities and needs a custom-designed system.

Finding the right team

Not every therapist or health care provider is properly trained to evaluate and prescribe the proper components for seating and positioning.

There is no formal training or testing to accredit health care providers who specialize in seating and positioning. RESNA, an organization of rehabilitation professionals, is developing guidelines that may be used to certify specialists in this area.

Parents need to ask about their team's experience-What seating and positioning equipment have they worked with, how many years have they worked in the seating and positioning field, and what type of conferences and training programs do they attend?

Although some professionals may be offended when asked about their expertise, these questions are important. "Why do we feel comfortable asking the qualifications of the TV

> repair man but not the people looking after our health?" asks Trefler, adding, "If the professional is not willing to share—or if they become offended-the parent might need to go elsewhere."

A qualified team will make sure the parents are involved with the evalua-

tion and the choice of seating and positioning equipment. Trefler advises parents to ask themselves, "Are they (the parents) just going to a clinic and being told what's right or are they truly being included as one of the team members?"

A qualified evaluation team should: Ask parents about the child's

lifestyle, his or her environment at home and school and overall community involvement. Ideally, the team would be able to observe the child in these different environments.

• Use techniques to simulate different positioning options. This can be done with a seating simulator, a device that simulates different systems by changing seat and back angles and positions. Simulators help determine the correct size of the system and its different accessories.

If a simulator is not available, the team should use various mobility bases, such as wheelchairs, and positioning components, which may include different seats and backs, to simulate different options.

- Use a pressure mapping system to help avoid pressure sores, known technically as decubitis ulcers. Children who are unable to shift weight independently in a system or lack sensation in parts of their body are prone to sores. Sores can lead to dangerous infections, discomfort and costly treatment. Many cushions have been developed for pressure
- · Consider the child's use of technology, such as computers, augmentative communication devices or any other devices that improve the child's quality of life. The child should be positioned in order to take full advantage of these technologies.
- When possible, ask the child what he or she is comfortable with. This includes questions about the different angles and equipment arrangements and color and fabric preferences.
- Help parents find funding.

Standers and bed positioners

Parents can also want to ask about therapeutic positioning devices such as standers or bed positioners. Again, parents will want to make sure they are involved with the evaluation and selection process and that the team is qualified to evaluate their child.



KISS (Keep It Simple Simulation) Simulator by Pin Dot



What to buy

There is no one formula that can be applied to every child to determine proper seating and positioning. Because of the ever-growing commercial availability of different equipment, customized systems (those created specifically for a particular child) may not be necessary. Instead, parents may be able to purchase different components that could be used together to create a suitable



The Chameleon, a three-in-one infant stander, by J.A. Preston, Jackson, MI.

system recommended by the team.

When possible, a child can try out the equipment before a purchase is made. Although customized systems usually cannot be tried out before purchase, dealers can loan parents different pieces of equipment for the child to try at home overnight.

Stand back and look

Most children will have to be revaluated every two to five years for a new seating system. Cushions in the systems may need to be replaced more often because of wear and tear and the loss of pressure-relieving qualities. If the total system design is not being changed, parents can buy new cushions directly from dealers without consulting the evaluation team.

The system may need to be changed if the child:

- Is unable to maneuver objects as easily as in the past.
- Looks uncomfortable or complains of discomfort.
- Has gained substantial weight.

 "If there's anything we can teach

therapists and parents, it is to stand back and look," Trefler says. "Look at the child and how she is functioning. They'll spot problems."

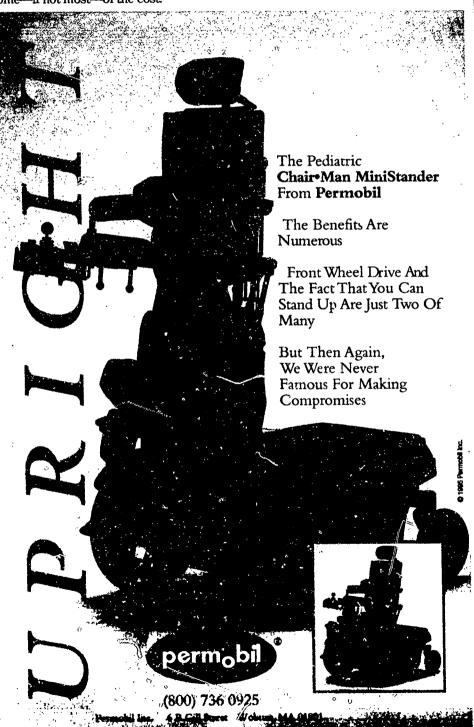
Fitting the bill

Seating and positioning equipment costs range from hundreds to thousands of dollars depending on the child's needs. Most health insurance companies or Medicaid will pay some—if not most—of the cost.

Insurers are likely to pay if the evaluation team justifies the cost. If parents need additional funding after insurance benefits are used, they can ask equipment dealers and/or contact local service organizations.

-Marc S. Malkin

Thanks to Elaine Trefler, M.Ed., OTR, FAOTA (Fellow of the American Occupational Therapy Association) for her help in compiling this article.





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Resilience

The tendency

for a child.

adult or

family to

stressful

activity and

success.

recovery.

Resilience



Children's Health Notes

Project Resilience:

What Are We Learning?

After two interviews conducted approximately 18 months apart with the 120 families that make up the Minnesota infant cohort, the research team wanted to know: Does family functioning change following the diagnosis of a child's chronic condition?

It turns out that most families continue to do well within two years of diagnosis. Some 76 percent of the families report there is no change in family functioning.

However, a significant number of families say they struggle with the effects of providing care for their child with a disability. At the time of the second interview, 21 percent of families report they are experiencing a change in their family's ability to function. This change in their ability to successfully accomplish tasks and roles and with their success in

INSIDE

The Canter for Children with Chronic liness and Disability is learning a great deal about children with dirent lilness and withings, their families, and the political, mith case, and policy environments that seffect their tare. To reach as many families as we carry we take with Exceptional Parent to publish Children's Elestite Notes to define the referencests raise questions, identify strategies, or provide sienal cation of wanter at one critical to providing care for children

communicating with one another can also be seen in the way both the father and the mother interact with their child. Parents may be a little distant, engaging less in playful communication.

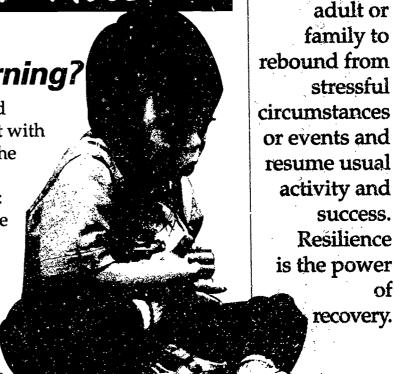
Mothers in this group report that characteristics of the chronic condition contribute to the stress in their lives. This is particularly true when their children have cognitive, respiratory, sensory and mobility disorders. Fathers report that marital adjustment, characteristics of the chronic condition, and

the father's depression contribute to a decline in

the way the family

functions.

The analysis of this data show child behavior problems are not determined by the chronic condition only. Mentally and physically healthy parents and the healthy functioning of families are "protective" factors that enhance resilience in the first 18 months after diagnosis. These changes might indicate an overall change in functioning, but that conclusion requires further study.





Childrens Health Notes

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What Kinds of Activities, Behavior & Relationships Promote Resilience in Families?

More and more, we find examples of children and youth who seem to thrive despite what appear to be overwhelming odds.

And it's not just those like Marlee Matlin who becomes an Academy Awardwinning actress despite being deaf, or Judy Heumann who becomes a teacher and then Assistant Secretary of the Office of Special Education & Rehabilitative Services (OSERS) despite her quadriplegia and need to use a wheelchair.

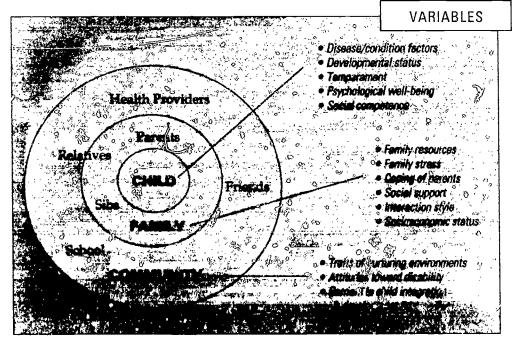
It's the 10-year-old who, after several amputations, writes the humorous short story, "The Leg with an Ego."

■ It's the plucky 8-yearold with cerebral palsy who goes to school with your son or daughter and is getting A's!

What makes these children and youth able to accomplish the "developmental tasks of childhood," to allow them to "fit in" and thrive?

Most physicians and therapists, teachers and social workers spend their time diagnosing and treating what's wrong with a child who has a chronic illness or disability. Rather than dwell on the weaknesses, we wanted to know "What are the strengths

of children and families?" So we began asking these questions more than five years ago as part of Project Resilience, a longitudinal study of factors predicting competence in children with chronic illness. This study is designed to investigate, over time, the risk and protective factors associated with optimal psychological, behavioral, and social functioning and development of the child with chronic conditions and his or her family. Included here is a preview of some of the earliest findings.



Project Resilience, the Center's longitudinal study of children with chronic conditions, seeks to learn what kinds of activities, behavior, and relationships promote resilience in families.



RESEARCHERS

Robert William Blum, M.D., Ph.D., Joän Patterson, Ph.D., Randy Stinchfield, Ph.D., and Ann Garwick, Ph.D., were co-presenters at a symposium, "Understanding Resilience in Families of Children with Chronic Conditions," during the Annual Meeting of the National Council on Family Relations held in Minneapolis, MN, on Nov. 8-13, 1994. The information presented here is based on that presentation. Blum, Stinchfield and Garwick are members of the Division of General Pediatrics & Adolescent Health in the University of Minnesota Medical School, and Patterson is in the Department of Maternal & Child Health, School of Public Health, at the University of Minnesota. Their in part, by the National Institute on Disability and Rehabilitation Grant



research is supported, #H133B40019.

around Seattle, Washington. Our goal is to understand what distinguishes the child with a chronic illness or disability who grows up to work well, play well, love well and expect good things.

Background

Just What Is A Longitudinal Study?

The purpose of longitudinal research is to study the lives of children (or any group of people) over time—a long time sometimes a generation. Researchers at C3ID propose to study the growth and development of children, in some cases, from the diagnosis of a disability within the first year of life through to adulthood.

Project Resilience involves 330 children with chronic conditions and their families. By design, the children who are participating are affected with a range of conditions—from heart disease to juvenile arthritis, epilepsy to blindness. That's because we, like others, believe that the impact of chronic illness and disabilities on a child's development is more similar across conditions and disabilities than different. Families respond to questionnaires, and trained interviewers ask standardized questions,

conduct and record interviews, and videotape interactions between children and parents. What we learn could influence program and policy development.

C3ID isn't the first to conduct a longitudinal study of children. Many of our assumptions come from a 30-year study of the roots of resiliency and the sources of strength and vulnerability found in a multiracial group of children who grew up in poverty on the Hawaiian Island of Kauai. These researchers, Emmy E.

Werner and Ruth S. Smith, show that a balance between risk factors, stressful life events, and protective factors within the child and the environment accounts for the range of adaptive (and maladaptive) outcomes in human development.

Approximately half of the families C3ID are studying were recruited within the first 18 months of their child's diagnosis. With this infant cohort, research staff are examining the course of development from the first year of life. The other participants were recruited when the children were between 8 and 10 years of age. These preadolescents will help us understand the added challenges of adolescence. About half of all participants live in the Twin City area; the other half live in and

FOR MORE INFO

If you want to read more about Project Reallience, you can read the following journal articles: Vulnerability and Resilience of Children said Their Paralles, problemed in Pediage Aventy Levels of Meaning in Family Stores Taxony,

When Physicians First Talk to Parents:

Heading Families in the Right Direction

Families vividly remember the time when they learned about their child's condition.

That's why C3ID interviewers tape record families' responses to these questions:

- Would you go back to the time when you first learned about your child's condition and talk about what happened?
- What were you told?
- Who told you?
- What were your reactions?

Drawing on the responses of families with children diagnosed with

Down syndrome, families with children diagnosed with congenital heart disease, and families with children diagnosed with both, researcher Ann Garwick discovered most talk about the sensitivity of the health care professional and the quality of information that person provides.

Families learning to accept their child with Down syndrome worry about the future and talk a great deal about the future when their child will be a young adult.

However, parents whose children are born with life-threatening heart disease recall the fear and anxiety about the immediate outcomes. They describe coping one day at a time with little vision of the distant future.

Interestingly, when a child was born both with Down syndrome and congenital heart disease, the issues overlap. Sometimes what is first on their minds depends on the particular issue with which they are dealing.

This qualitative study concludes that how parents are informed that their child has a chronic illness or disability affects how the family functions in the first 18 months of a child's life. Parents' responses indicate that health providers need to really evaluate how they talk to families.

Families had negative reactions to first learning of a child's diagnosis in the presence of strangers or by telephone. Many indicated that they had received outdated or inadequate information.

Families had positive reactions to health care professionals who were supportive and sensitive to their feelings, kept them informed about their child's condition. and focused on their child as a whole person.

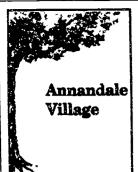
Before talking to families, the professional should consider an individual family's background, including: pregnancy, labor and delivery experience, expectations for a healthy child, condition of the child and parent(s), beliefs about chronic illness and disability, knowledge and experience with the child's type of condition, awareness of media portrayals of the child's condition, and the relationship between the family and physician.

The Center for Children with Chronic Illness and Disability was established in October, 1989, and is housed at the University of Minnesota. The organization is a research and training center dedicated to the study and promotion of psychological and social well-being of children with chronic conditions and their families.



RESULTS

Breaking the news of a child's disability or chronic condition is a critical event for families. Ann Garwick suggests that health professionals P*A*C*E the News: the setting. family's background. strategies that best fit he family and their situation. Their understanding



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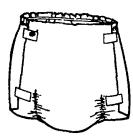
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103	AccessAble Environments	7
2	Adaptive Design Labs	
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39	Barrier Free Lifts	
11	Children's Specialized Hospital	8
180	Clarke Healthcare Products	40
150	Columbia Medical	
151	Columbia Medical	10
181	Cotting School	50
124	Crystal Springs School	45
74	Cumberland Hospital	16
182	Danmar Products	
107	Devereux Foundation	
105		
	Diestco Manufacturing	
184	E-Z-On Products	
123	Equipment Shop	56
31	Estate Planning	56
106	Evergreen Center	
156	Everyteen Content	50
	Express Medical Supply	/
132	Flaghouse	19
135	Ford	5
166	Haverich Ortho Sport	6
14	HDIS	
185	Health Hill Hosp. For Children	٥
3	Heartspring	
	nearisping	اد
90	Humanicare International	33
110	Innovative Products	52
42	IntelliTools	7
56	James Leckey Design	15
147	Jay Medical	3
	Kaleidoscope	رع د
70	Kennedy Krieger	
	Kernieuy Krieger	32
98	Kid-Kart/Kid Care	11
45	Laureate Learning	
16	Marblesoft	8
67	Mulholland	C2
76	New England Center for Autism	
165	Olsten Kimberly QualityCare	
103	Desert Core Inc.	20
	Parent Care, Inc.	50
186	Permobil, Inc	
26	JA Preston	
183	Prime Engineering	t
63	Racing Strollers	. 57
17	St. Joseph's Hospital & Medical Center.	
108	Manchen Bodiston Facility	
	Voorhees Pediatric Facility	20
91	Willow River Farms	45
72	Woodbury Products	15

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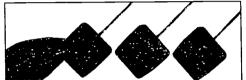
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For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216, V/TTY, (301) 588-9284, V/TTY or (301) 587-1967, FAX.



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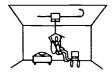
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# ASK THE DOCTOR

by David Hirsch, M.D.

# **Toilet Training**

We have a seven-year-old daughter who is blind due to retinopathy of prematurity and has an amputation of her right leg above the knee for which she wears an artificial limb. She has mild cerebral palsy and is unable to sit unsupported. She often gets constipated.

We are trying to toilet train her but we are having problems because we have to remove her prosthesis to put her on the toilet. This causes her to become even more unbalanced. We think that toilet training is very important. Do you have any suggestions?

A lagree that toilet training is important for your daughter, not only for purposes of hygiene but also for her self-esteem. However, it is important not to toilet train her before she is ready. That could delay the process and even make her constipation problem worse. However, if she shows the proper interest in toilet training, you can try it.

First, you need to set up a mechanism so your

Ask the Doctor is a regular department of EXCEPTIONAL PARENT in which questions are answered by David Hirsch, M.D., a pediatrician and member of the Editorial Advisory Board of EXCEPTIONAL PARENT. Dr. Hirsch is a partner in Phoenix

daughter can sit on the toilet without losing her balance. This is essential for any child who is being toilet trained. You may want to have something she can hold onto with her hands.

If she is still small enough, you may be able to use a toilet seat or a potty chair, which is less intimidating. Take her to the toilet any time she asks to go. In addition, try taking her to the toilet after meals or at a time of day when she typically has a bowel movement.

Constipation will make toilet training more difficult. Try to increase her liquids in the form of natural juices and water. Unless she is on a special diet, you can increase the amount of fiber in her diet by increasing fruits and vegetables and decreasing the more constipating foods such as dairy products.

Clearly, you have come a long way with your daughter. Be patient, and toilet training will be another obstacle she will overcome.



Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

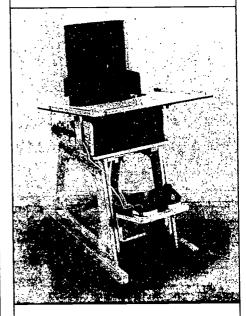
Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with the child's regular physician and other appropriate professionals. When Dr. Hirsch mentions specific products or medications, he is illustrating his suggestions; he is not endorsing any specific products.

To submit a question, write or fax: Ask the Doctor, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, Fax: (617) 730-8742.

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Circle # 2



# HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

# SSI Rejections and Appeals

Our i2-year-old son is blind and mentally retarded. He also has cerebral palsy and hydrocephalus. Costs for his care are astronomical.

Several years ago, I applied for SSI for him because the level of his disabilities make him eligible for the benefits. After several interviews and countless forms, he was ruled ineligible because our income was too high. While our income seems high, once you start subtracting the cost of all my son's special needs, very little remains for the rest of the family.

I accepted the ruling. Since then, I have read that appeals are almost always successful. Is that true? Do you think that our family would have a chance of winning an appeal now?

B.F., Virginia

A This problem occurs frequently. It is frustrating for families with average or above-average incomes. SSI and the Medicaid health insurance benefits that generally accompany it were designed to meet the needs of people with limited incomes who have severe disabilities.

Although a family with average or above-average income may not have enough money to meet all of their child's special needs, family income may make the child with a disability ineligible for SSI or Medicaid.

# **Exceptions to income rules**

There seem to be two exceptions to the eligibility rules. First, there is a special provision in the regulations for Medicare—rather than Medicaid—coverage for a child with kidney failure, even when a family's income exceeds the general Medicaid limits.

Second, there is a special waiver in the Medicaid regulations that provides for Medicaid coverage when a child with a disability is hospitalized and where at-home treatment would be appropriate and is less expensive than hospital-based treatment. In some states, this special waiver may apply even when the family's income is higher than the usual Medicaid guidelines. Aside from those exceptions, a family must meet eligibility rules to qualify for SSI or Medicaid. However, the rules can be rather complicated. And since eligibility rules differ from state to state, the situation is more complex than for other government programs.

In addition, eligibility rules in regard to income are different for SSI and Medicaid in many states. Several states, for example, have special rules that allow a family to deduct the cost of some medical expenses for a child with a disability in calculating total family income. Those rules, however, generally apply only to Medicaid eligibility, not to SSI.

I think that rejection of an SSI/Medicaid application should almost always be appealed, at least to the first level. The general rule is that an appeal should be filed within 60 days of a rejection. However, it's never too late to consider filing an appeal or a new application.

There are four different levels of appeals; they usually follow a specific order. The first level involves a request that another person within the local Social Security office review the application. If that does not result in a satisfactory decision, the second leve' involves a hearing before an administrative law judge.

The third level involves a review by the Social Security Administration's Office of Hearings and Appeals. And the fourth level involves filing a lawsuit in federal district court.

Appeals often result in a decision to grant SSI and/or Medicaid benefits, but there is no guarantee. However, the appeals process is fairly simple. Usually, you do not need an attorney, except at the federal court level.

The Arc, a national organization on mental retardation, offers free information on SSI and SSI appeals. Contact The Arc, 500 E. Border St., S-300, Arlington, TX 76010, (817) 261-6003 (voice), (817) 277-0553 (TTY). Ask for Social Security and SSI Benefits For Children With Disabilities and Appealing a Social Security Disability Benefits Decision. Send a self-addressed, stamped envelope.

The Social Security Administration also has two free booklets available on SSI benefits for children with disabilities. Copies may be available at your local Social Security Administration office. Or call (800) 772-1213 (voice); (800) 325-0778 (TTY).

You can get advice on appeals from your local legal services office. Contact the National Legal Aid and Defense Association, 1625 K St., NW, Ste. 800, Washington, DC 20006, (202) 452-0620 (voice) for the nearest office. Local Protection and Advocacy offices may be helpful, too. Call the local bar association for the nearest office.

Richard Epstein answers readers' questions about health insurance.

Send questions to
EXCEPTIONAL PARENT;
209 Harvard St.,
Ste. 303, Brookline,
MA 02146. Fax questions
to (617) 730-8742.

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. To ensure privacy, only your initials and state will be used in the column. Due to time constraints, it is not possible to respond to letters individually.



# Networking

# Information from The National Parent Network on Disabilities

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#### DON'T FORGET

Mark your calendars! NPND's next Annual Meeting will be held in Washington, Sept. 30-Oct. 2, 1995. Contact NPND for more information.

#### Thanks

NPND wishes to acknowledge and thank American Airlines and the National Association of Medical Equipment Suppliers for generously supporting our 1994 Annual Meeting and Reception.

# **IDEA at Crossroads in New Congress**

As Exceptional Parent went to press, the 104th Congress had been in session for two weeks. Although the first 100 days of this session are dedicated to passing the major components of the Republican's "Contract with America," the Individuals with Disabilities Education Act (IDEA) is also scheduled for reauthorization during this session.

It appears that IDEA will be attacked in a variety of ways during the reauthorization process. This Networking is devoted to providing information for parents and professionals to respond quickly from an informed point of view.

Included are summaries of potential attacks on IDEA, along with positions of the National Parent Network on Disabilities (NPND). For a full understanding of these issues, NPND encourages family members and professional to join NPND's Family Action Network (FAN). FAN will keep you up to date with developments in Washington.



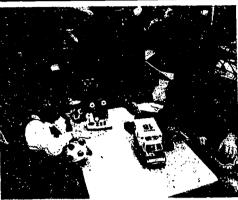
The Heritage Foundation, a conservative Washington think tank, has recommended the repeal of 24 laws as part of a briefing for new members of Congress. IDEA was one of these laws.

• NPND Position: This challenge to IDEA has the greatest ramifications. While Part B of IDEA (all procedural safeguards regarding access to a free, appropriate education) is permanently authorized and does not face the challenges of reauthorization, it can be repealed. It is impossible to estimate how real the threat of repeal is at this time. It is significant, however, that the repeal has even been mentioned to new members of Congress who have not participated in previous discussions of this legislation.

# Unfunded mandates

Senate Bill #1 (S1), principally sponsored by Republican Sen. Dirk Kempthorne of Idaho, is a bill which would limit Congress from imposing mandates on states without authorizing federal funds to help implement the mandates. S1 and its companion bill in the House of Representatives are racing towards passage. It appears that both IDEA and the Americans with Disabilities Act (ADA) will be exempt from this legislation, although there has been no written assurance of this from the many co-sponsors of these bills.

• NPND Position: NPND remains concerned because some of the criticisms of IDEA and the ADA have categorized these laws as unfunded mandates. As defined by S1, it



Megan Donnelly plays with Miss America 1995, Heather Whitestone, and NPND executive direcior Patricia McGill Smith at the Herald Center Trus "R" Us store in New York City during the unveiling of the second edition of the Toy GUIDE FOR DIFFERENTLY-ABLED KIDS.

appears that these laws are not unfunded mandates. NPND opposes any amendments to the legislation that would deem IDEA and the ADA unfunded mandates.

#### APPROPRIATIONS

Key members of the new House leadership have announced that the budget resolution will be the "transformational" document of this Congress. Congress can effectively abolish programs by failing to fund programs. Accordingly, programs do not have to be repealed, just not appropriated. Given the massive amount of cuts needed to balance the budget, it seems likely that the programs we care about—like SSI (Supplemental Security Income), IDEA, Medicaid and others-will suffer significant cuts.

• NPND Position: The budget offers many opportunities for cutting. No programs should automatically be taken off the table. All waste should be cut. In particular, defense spending should be reduced (along with many other programs) and not increased as it is now proposed.

These are just a few of the pressing concerns that face us in the current Congress. Everything is on a fast track! Things seem to change hourly. We must be more vigilant than ever.

In the words of Justin Dart, "We are now in the Valley Forge of our movement." We must remain unified! We must act to defend the rights of people with disabilities and the programs that empower us all.

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Circle # 123

# Life Planning Should Be A Team Effort

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## Richard W. Fee Executive Director

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## Circle #31

# EXCEPTIONAL PARENT / FEBRUARY 1995

# **Family Action Network to Save IDEA**

The Family Action Network (FAN) to Save IDEA is NPND's special project to ensure that children with disabilities maintain their federal right to a free, appropriate public education.

# WHY FAN NOW?

Some members of the new Congress are seriously considering declaring IDEA an "unfunded mandate." Additionally, the Heritage Foundation, a conservative think tank, has called for the repeal of IDEA. If IDEA is repealed, children with disabilities will only have the rights granted by their states.

# PART H OF IDEA

If IDEA becomes defined as an unfunded mandate, children may lose services through Part H, a 1986 amendment to IDEA that does not require states to provide early intervention to children from birth to age three, but offers federal dollars to states interested in serving this age group. If IDEA is nullified, children will receive only the services each state decides to provide.

# WON'T THE COURTS PROTECT MY CHILD?

If IDEA is repealed, the last 20 years of court decisions will be meaningless. There will no longer be a federal law on which to back court decisions. NPND worries that if the federal law is nullified, states will also decrease—or even eliminate—services.

# WHY DOES NPND THINK IDEA MAY BE REPEALED?

Although they have not said it outright, many members of the new Congress have indicated that IDEA will be seriously weakened, if not done away with altogether. Members of Congress are being urged to repeal IDEA by our opponents. Coupled with the movement to declare IDEA an unfunded mandate, it is distinctly possible that IDEA will not survive the 104th Congress.

# EVERYONE CAN HELP

You can help save IDEA by joining FAN. FAN members will receive quarterly newsletters with updates on how IDEA is faring in Congress. Alerts of timely information and requests to take action to help save IDEA will be sent when necessary.

# PROFESSIONALS WELCOME

NPND urges educators and other professionals who work with people with disabilities and their families to join as a "Friend of FAN." We need all the friends we can get!

# 

National Parent Network on Disabilities, 1600 Prince St., Ste. 115, Alexandria.

VA 22314, (703) 684-6763 (V/TTY), (703) 836-1232 (fax).

# WHAT'S HAPPENING



Kyle is the newest regular on THE PUZ-ZLE PLACE, a PBS series teaching meschoolers to celebrate diversity. Kyle, who uses a wheelchair, makes his debut in the 'Willing and Able" episode,

scheduled to air Thursday, March 9. Check local television listings.

# The National Parent-to-Parent **Support and Information System**

(NPPSIS) is a matching service recently funded by a four-year grant from the Maternal and Child Health Bureau. NPPSIS is creating state fact sheets listing health care reform information, resources, government contacts, medical services and parent advocates. They also keep track of children, diagnosed and undiagnosed, whose parents are looking for a match.

NPPSIS tries to match parents with a "veteran parent" who has an older child with a similar condition and is willing to provide guidance and support.

To sign up as a parent in search of a match, a parent willing to serve as a veteran or both-contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513, (800) 651-1151 (V/TTY), or (706) 632-8830 (V/TTY).

Kids' Hall of Fame by Pizza Hut is an annual search for kids up to 14 years of age who have made, or are making, a positive difference for themselves or the world around them. Five Hall of Fame inductees-each receiving a \$10,000 post-high school scholarship and a crip to Washington, DC-will be announced in the spring. Runnerups receive \$50 or \$100 U.S. Savings Bonds. Nomination forms are available at Pizza Hut restaurants or by sending a SASE by Feb. 28 to Kids' Hall of Fame, P.O. Box 92477, Libertyville, IL 60092. Entry deadline is March 15.

The staff of the EXCEPTIONAL PARENT publishing office in Hackensack. New Jerseu joined children parents and staff for a December holiday party at the Hackensack Medical Center's Institute for Child Development. Toys for the children



were donated by Steven Kanor of Toys for Special Children and R.J. Cooper of R.J. Cooper & Associates.

Joseph M. Valenzano, Jr., EXCEPTIONAL PARENT president and publisher, is the fellow in the red suit and white beard. Helping him out is elf Terri M. Sutera, vice president of marketing.

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Circle # 63



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# CHILDREN'S PAGE

# ALEX'S PHONE CALL

by Doug Bittle

y little brother is named Alex. He is nine years old and has Down syndrome. Alex went to a special education school for three years and never really had a social life of any sort except with our own family.

Although his old school was good for him when he started there, it changed after a while.

It seemed he would be better off with kids who did not all

Alex loves skiing. Two years ago, he enjoyed a winter vacation with his family in Crested Butte, Colorado. so significant about this phone call is that it was Alex's first phone call!

One problem is that Alex is not very conversational and when the friend called—just to talk—the friend had to do most of the talking. My mom and I helped Alex out. It was pretty cool that Alex got a phone call from a friend.

The kids at the new school also accept and encourage Alex. Last week, he read four sentences in

front of the class and the kids in his class all clapped for him. One of Alex's biggest problems is that sometimes he just chooses not to talk although he can understand you. He has always been like this. I think the new school will help

> him to talk more because he has more friends.

Alex smiles for

his 1994 school

portrait at

Bethesda Ele-

mentary School.

Unlike many children going to school, Alex happily boards a school bus every morning at eight o'clock. Alex is a great little brother and I'm glad he has friends at his new school.



Alex and Chris play lacrosse with their cousin, Chris Lyons (back to camera).

have disabilities. So, my mom decided to have him go to

Bethesda Elementary School. Now, he is in a regular fourth grade class. Sometimes an aide helps him when he needs it.

Tonight (November 7, 1994), I answered the phone and it was Jeffrey, a new friend of Alex's at his school. He was calling for Alex. What was

Doug, 12, lives with his parents, Pat and Greg, and brothers Alex, 9, and Matt, 14, in Garrett Park, Maryland. He is in the sixth grade at Tilden Middle School. Doug enjoys sports, especially football, basketball and in-line skating.

**THE CHILDREN'S PAGE** welcomes contributions from children with disabilities and their siblings. Be creative! Send your stories, photos and artwork to: CHILDREN'S PAGE, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.



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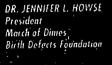
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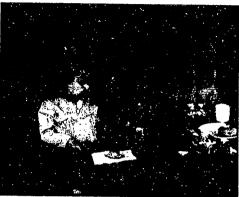
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# CEPTIONAL DARENT

MARCH 1995 VOL. 25, ISSUE 3

# Mobility

Mobility—"The devil is in the details"	23
Obtaining Specialized Equipment by Adrienne Falk Bergen	
Finding a Rehabilitation Technology Supplier by Dan Lipka	31
Powered Mobility? by Phil Reppert	32
Controls for Power Wheelchairs by Peggy Barker	34
The Art of Manual Wheelchair Maintenance by Mary Angelico	38
Features	
One Day at a Time by Katharine Byers	19
A family learns to live with epilepsy.	
Special Needs in the Lunchroom by Gloria Frolek Clark	45
Modifying school meals for students with special eating or nutritional needs.	40
Choosing a Summer Camp by Jennifer M. Koerber	^^
Income Tax Tips	60
by L. Mark Russell, Arnold E. Grant and Richard W. Fee	
Departments	
Editor's Desk	2
Letters	4
Search & Respond	8
Familiar Faces	17
What's Happening	47
Ask the Doctor: Infantile Spasms	48
Health Insurance Troubleshooter: A New Insurance Pian for Individuals Considered "High Risk"	53
Fathers' Voices: A New Perspective on Development by Louie Mauro	
Role Models: Tony Coelho	
Directory of Advertisers	62
New Products	
Youth Connections	
Exceptional Parent Library	
Children's Page: My Wheelchark oy Emily Brush	



PAGE 25

Cover: Ten-year-old Clark Byers enjoys a snowy afternoon at a park near his Bloomington, Indiana home. In this issue, his mother, Katharine, describes how the family has learned to live with Clark's epilepsy. See "One Day at a Time," page 19.

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# EDITOR'S DESK

nice upon a time, all wheelchairs looked alike. One size was expected to fit all, and consumers (parents and individuals with disabilities) had little or no participation in the decision-making process.



STANLEY D. KLEIN, PH.D.

Today, many mobility products are available to allow children or young adults with physical disabilities to participate fully in community life. This preponderance of choices has made the selection process more complicated than ever before. Identifying the most appropriate equipment for a child or young adult requires careful assessment and collaboration by parents and professionals.

Our sixth annual mobility issue offers a road map to this process. For help, we turned to Adrienne Falk Bergen, RPT. Adrienne has spent many years answering mobility questions and training therapists and other mobility professionals. With Adrienne's help and the help of her colleagues, we have included

articles on the selection process, the roles of the people involved, powered mobility and manual wheelchair maintenance. This issue also includes some personal perspectives from parents and, on the *Children's Page*, from eight-year-old Emily Brush.

# Much more than mobility

There's lots more in this issue for parents and for professionals. In "One Day at a Time," Katherine Byers describes how her family has learned to live with her son's epilepsy; in *Role Models*, Tony Coelho shares his experiences as a person with epilepsy.

For families beginning to make summer plans, this issue includes information on camps. And *Youth Connections* explores the transition concerns of teenagers with disabilities and special health care needs and their families.

## **Feedback**

We continue to receive wonderful feedback about our December (1994) issue on religion and our 1995 Resource Guide (January). We have published some of these responses; we wish we had room for all. Thanks to all who have written and called.

We also continue to receive feedback—largely negative—about the fact that *Exceptional Parent* accepts advertisements from private, special-education programs. It seems that some people concerned with the education of children with disabilities insist that everyone—including this magazine—support the inclusion of all children in public schools. Our perspective is different. Since the first issue of this magazine appeared in 1971, *Exceptional Parent* has advocated for the position that parents are the best experts on their children and are capable of making good choices on their behalf—in education, health care, recreation and every other area. We are also advocates for inclusive education when such programs include the necessary supports for everyone involved. At the same time, we are very leery of programs masquerading as inclusive education—but actually implemented as cost-cutting measures—that fail to provide support for children's individual needs.

## On Capitol Hill

In our February issue, Justin Dart's guest editorial ("All Together Now") and *Networking* (from the National Parent Network on Disabilities) expressed concerns that Congress might cut programs supporting the independence of children and adults with disabilities and their families. On the basis of recent news reports regarding proposed changes in SSI (Supplemental Security Income) regulations, we urge readers to contact legislators to let them know that programs like SSI are critical and cost-effective. At the same time, we know some federal programs need improvements; share suggestions for changes with your congressional representatives as well.



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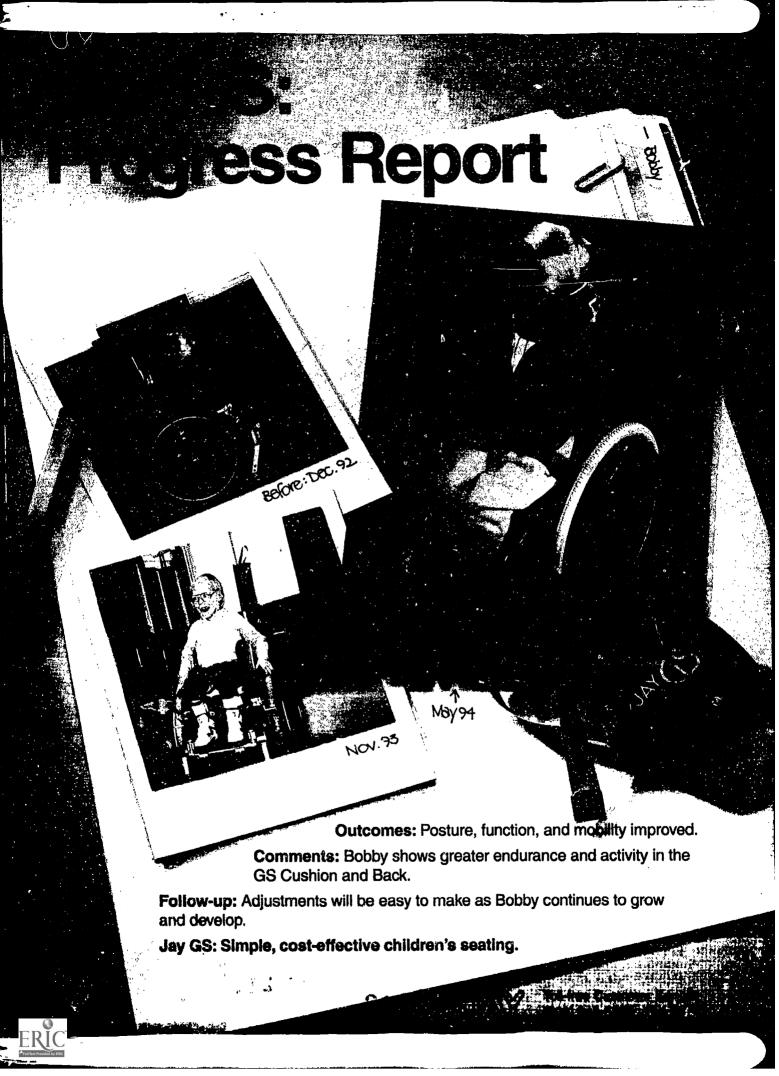
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For subscription and advertising information, see page 62, BPA International Consumer Magazine Membership Applied for August 1993



# LETTERS

# **Religious Participation for All**

The phone rang the other day, and the voice at the other end identified herself as Ginny Thomburgh (author of "For the Love of Peter," December 1994). You cannot imagine my surprise, delight and honor that she would call me just to chat about our special children and the very real need to include them in all aspects of life, especially religion. Her call had been prompted by my letter to the Religion and Disability Program of the National Organization on Disability (NOD), which had been listed in the directory of "Faith Group Resources" in the December issue of Exceptional Parent. Although I had read that issue at the end of a long day, I had pushed myself to write to all the Jewish organizations and to the National Organization on Disability. I never realized I was writing to Mrs. Thomburgh! That one call from her erased a lot of the hurt we have felt because of the lack of response from our own religious group.

Although our son attends our temple's religious school, this is more because we sought out a small synagogue that would welcome us as a family rather than the existence of any special accommodations. The December Exceptional Parent was a vital, alive issue—we thank you for devoting an entire issue to this aspect of life. My only sense of sadness was that it took a sectarian magazine to provide me with access to these resource organizations; the access did not come from our religious community.

As parents, if we had one wish, it would be to find a way to distribute the December issue of *Exceptional Parent* to all clergy. For all the strides the disability community has made, the greatest barrier is still lack of awareness.

We extend our appreciation for the sensitive way the December issue was handled. The contacts we have made from that issue will keep our fires burning so we can continue to educate those we meet about our special needs rather than just walking away. It can be a never-ending, exhausting task, but we think our children and the world that encounters them will be a little richer as a result.

G.F-H. & G.F-H., California

☐ Bravo to you! What an excellent issue on religion and people with disabilities! My four-year-old son, Bryce, has spina bifida. He is very Involved in our church; in fact, church provides most of his socialization opportunities. He asks to go to church almost every day. During his last IFSP (Individual Family Service Plan) meeting, a teacher commented that Bryce got a lot of socialization from being out in the community and in church. At the time, I thought, "Hey, we ought to write that in as part of the plan." Next time, we will!

One program that should be included in your directory of "Faith Group Resources" is the AWANA Clubs International (One East Bode Rd., Streamwood, IL, 60107; 708/213-2000, voice). It is like a Christian scouting program, complete with uniforms and awards. It is an inter-denominational Protestant group that gives charters to individual churches. They have a "Friends" program for children with disabilities. Parents can contact them for more information and to find out which churches in their area sponsor a club.

Bryce loves his AWANA "Cubbies" Cub. Before I end this letter, I have to share a story about him. Bryce was

# Tell us about...

# ...helping your child make friends.

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harrard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.



From left, Bryce Olstad, Ethan Ungala, Michaela Nuss and Cassie Ekwall listen to a story during a meeting of the AWANA Cubbies Club at Ashland Bible Church in Ashland, Oregon.

learning a Bible verse for his Cubbies club: "Children, obey your parents." I was so proud of him for learning it and wanted to show him off to some friends. So I asked him to say his verse. He promptly and clearly said, "Children, open your presents."

Thanks again for an exceptional issue!

Rachel Olstad, Talent, Oregon

# Success in Funding Van Adaptations

I'm writing in response to "Buying and Converting: What you need to know about van lifts and ramps" (December 1994).

Our four-year-old daughter, Jocelyn, has Walker-Warburg syndrome and uses a wheelchair. She weighs 45 pounds, and we are no longer able to get her in and out of a car seat.

We already had a mini-van when I began my search for funding to get portable ramps and a tie-down system. I was told the total cost for purchase and installation would be \$690.

I began calling social service organizations and fraternal clubs to see if financial aid was available. I spent more than a few hours on the phone, but was very successful! I was able to get money from Easter Scals, and the United Cerebral Palsy Association. This left our portion at \$40.50—very affordable.

I wanted readers to know that help is out there, if you're willing to spend some time finding it. Many of these organizations will also assist with funding for lifts.

J.F., Indiana

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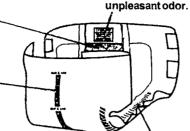
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# Felbatol

I deeply sympathize with the parents who were told by their daughter's neurologist that she should be weaned off Felbatol ("Ask the Doctor." December 1994). I am the parent of a seven-year-old son who has been on Felbatol for the past 13 months with dramatic results. While I support Dr. Hirsch's response, I think the parents should be advised to seek additional information to help them make the best decision for their daughter, in conjunction with their neurologist.

Our son had been taking Felbatol for nine months when the makers of the drug first began warning doctors of the risk of aplastic anemia and liver failure. We were terrified to learn that these very serious complications had been linked to this "miracle drug." Blood tests were immediately ordered for our son. Fortunately, they revealed no problems, and our son's neurologist recommended continuing the Felbatol.

Even though I trusted our neurologist, I wasn't ready to blindly accept this advice. This was my son's life we were risking, and even though stopping Felbatol may have meant the return of our son's uncontrollable, complex grand mal seizures, we sought to become as informed as possible before making a final decision. The Epilepsy Foundation of America was an excellent resource. After confirming, or in some cases correcting, what our neurologist had told us, the foundation gave us written, detailed information about the reported complications, the symptoms we should watch for and the precautions we should take. They even offered to contact our son's neurologist on our behalf.

Ultimately, we did accept our neurologist's advice to continue the Felbatol with frequent blood tests. Our son has now been free of grand mal seizures for more than a year with no sign of side effects.

D.L.P., North Carolina

Editor's Note: Readers may contact the Epitepsy Foundation of America at 4351 Garden City Dr., Landover, MD 20785-2267, (800) 332-1000 (voice), (800) 332 2070 (TTY), (301) 577-4941 (fax).



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# SEARCH

### Partial Monosomy 10/Partial Trisomy 15

Our 31-month-old daughter has partial monosomy 10 and partial trisomy 15. She has cardiac problems and global developmental delays. She does not walk or talk. We are interested in contacting parents of children who have the same condition.

S.M., Georgia

### **Near-drowning**

Six years ago, my son nearly drowned. He survived, but remains comatose. I have never seen letters from parents of similar children. I know most children don't survive this type of accident, but I am sure many do. I would like to know if anyone is doing research on this type of anoxic brain damage.

S.C., Florida

### **Persistent ATNR**

I have a 17-month-old son with cerebral palsy. He has a very persistent asymmetrical tonic-neck reflex (ATNR). This causes his right hand to constantly dig into the side of his face. I have to hold his hand during play, therapy and feedings. This is very frustrating for both of us! I would like to hear from other parents who have experienced this problem and may have some advice.

T.W., Iowa

### **Undiagnosed**

I have been trying to find a diagnosis for my daughter, Amanda, since her birth in September 1992. She was born with extremely low muscle tone, dislocatable hips and hypermobile joints. To resolve her hip problem, she wore a Pavlik harness until she was four months old. She started physical and occupational therapy at eight months of age and has continued to make progress in her physical development. She walked independently, with the use of ankle-foot orthoses (AFOs), just a few days before her second birthday.

Amanda is a bright and happy child who has excellent language skills. She has had echocardiograms, blood tests for muscle diseases, an electromyogram (EMG), nerve-conduction testing, DNA testing and ophthalmology exams. All results have been normal, with the exception of the EMG, which was scored as "borderline abnormal."

Following the abnormal EMG, we proceeded with a muscle biopsy. Based on the biopsy, doctors have said they think she has Duchenne muscular dystrophy. I have difficulty accepting this diagnosis because I understand that this type of muscular dystrophy is rare in females, is not evident at birth and is diagnosed with greatly elevated creatine phosphokinase (CPK) levels. Amanda's CPK level is within normal limits.

I am tired of hearing doctors say, "I have never seen a child quite like this before." I have a strong feeling that one of the readers of *Exceptional Parent* has seen a child like Amanda, and I would love to hear from anyone who might have some information to share.

D.N., California

# EXCEPTIONAL DARRENT The Measures for Passilies OGRO ORD OTHER DESCRIPTIONAL

- ➤ To reach out to parents of children with disabilities and special health care needs.
- ➤ To empower mothers and fathers by providing practical information and emotional support.

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### Congenital Hyperphosphatasia

Our daughter has been diagnosed with congenital hyperphosphatasia, a metabolic bone disorder. She is also

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday

challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clar';

Write or fax: Search or Respond Exceptional Parent 209 Harvard Street, Suite 303 Brookline, MA 02146-5005 Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923. New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in Exceptional Parent's 1995 Resource Guide (January 1995).

non-verbal and has severe intellectual disabilities.

When she was younger, she broke her legs several times, including both femurs. Her bones are becoming more deformed as she gets older. She can still walk, however, we recently ordered a wheelchair to use for longer distances. She communicates her basic needs with gestures and an Introtalker augmentative communication device.

We would like more information on this disability. She can't tell us what bothers her joints and bones; we would like to hear from anyone who could tell us what we can do to make her more comfortable.

M.B., Iowa

### **Chromosome Five Deletion**

Our 11-year-old daughter has a partial interstitial deletion of the long arm of the fifth chromosome. She is mentally retarded and has physical disabilities.

Pneumonia is a constant threat because she cannot move around except for rolling. We want to share experiences with other parents of children with the same condition.

B.B., Ohio

### **Chromosomes Two and Ten**

My four-year-old daughter has been diagnosed with a chromosome abnormality involving a duplication of material from the long arm of chromosome 2 and a deletion of material from the short arm of chromosome 10.

My daughter has low muscle tone and delays in all developmental areas. She has a kidney reflux and is being monitored by an ophthalmologist for the possibility of strabismus. We would like to hear from other parents who have a child with a chromosomal abnormality involving these two chromosomes.

K.S., Oregon

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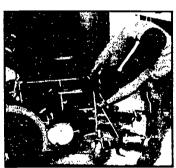
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# RESPOND

### **Disability Awareness** in Public Schools

M.G. (October 1994) has a 10-yearold son, Allan, with Asperger simdrome (a type of "high-functioning" autism) and some neuromuscular problems. He does well in regular science and social studies classes. M.G. wanted to hear about disability-awareness programs that have been used successfully in public schools to teach all students about disabilities.

I just want to add my comments on the importance of disability awareness in public schools. My son is 12 years old and has multiple disabilitiesmost of them "invisible"-including Tourette syndrome (TS) and obsessive-compulsive disorder (OCD). He is on medication for the TS, but has very minor motor tics. He is impulsive and has compulsive behaviors. All in all, he can be a "difficult kid."

particularly in unstructured situations like recess and lunch.

Before he started at a new school this fall, I made a point of meeting his teacher and the school counselor. I gave them a video and written materials on TS/OCD and a written narrative on how all this information applied to my son. I explained that he needed extra help and supervision.

The first week or two seemed to go well. My son talked about all the new friends he had made and how much he liked his new school. Then the prodictable decline began as his behaviors alienated the kids in his class who had no reason to try to understand him, since they did not know about his diagnoses.

I could see my son becoming increasingly tense, and I worried that if pushed far enough, he would strike out and hurt someone. I went to the school and talked with the principal. I told him what was happening and gave him a short videotape on TS that could be shown to the class. My parting comment was that some intervention needed to happen soon because I could see trouble on the horizon. That very day, my son and some other children were involved in a major fight on the playground. Everyone was hauled to the principal's office, crying and upset.

Fortunately, the principal had been prepared, and after settling the children down, he met with the school counselor, classroom teacher and my son to set up a class meeting for the next day. In that meeting, they planned to show the video on TS, allow the children to ask questions about the condition (including questions directed to my son who would be supported by his case manager), and have the children brainstorm ways to help my son at times when

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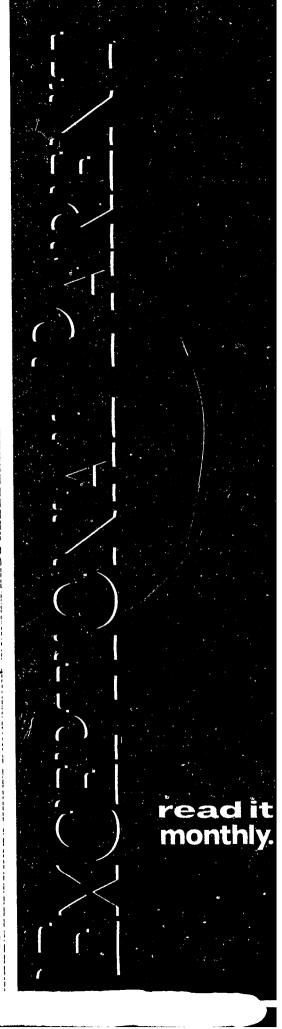
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people have done everything possible to make these absorbent underpants respect our kids like the grown-ups they soon will be.

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he seemed to be "losing it." He came home that day happier than he had been for weeks. He seemed relieved about finally getting everything into the open.

The next day was no disappointment. The class watched the video intently and had many questions about TS—When did you know you had it; can other people catch it; will you always have it? They also had many good ideas about supporting my son—from verbal reminders to him, to educating kids in the other classes about TS.

The effects of that day have been remarkable. My son is working hard in school, rarely has any difficulty with his peers and goes to school happily every morning. My best reward came one morning soon after the class meeting. As he was eating breakfast, he turned to me with a big smile and said, "Mom, all the kids in my class play with me!"

C.R., Oregon

### **Loud Noises in Public**

G.W. & J.W. (December 1994) have a six-year-old daughter, Kaitlyn, with severe intellectual disabilities. Rett syndrome has been ruled out, and Kaitlyn's parents do not believe she is autistic. Kaitlyn does not talk, but makes loud noises and high-pitched screams; her parents worry about how these noises will be handled when she starts kindergarten next year. They wanted to hear from anyone who has dealt with a child who has similar characteristics, and were especially interested in suggestions for getting Kaitlyn's noises "down to a reasonable pitch."

I do not have the answer to your question but our daughters seem similar so I decided to write. My six-year-old daughter, Katie Lynn, also has severe intellectual disabilities. The possibility of an autism diagnosis has come up several times. Soon, we should be receiving the results of a recent autism evaluation.

Like your daughter, Katie Lynn is completely nonverbal. When she is happy or excited, she flaps her arms and utters a high-pitched scream. Depending on the situation—for example, in church or at her sister's choir performances—this behavior can be embarrassing for the family. But as odd as this behavior might seem to the general public, these screams are Katie's only means of communication. It is her way of expressing pleasure, and I will not discourage this behavior just so she can fit society's picture of normality. Katie is forced to modify her behavior in other areas; we have decided that this is one area in which society will have to make the adjustments. In situations where her utterances are disturbing to a group of people, my husband or I will take her out of the room until she is calmer.

Katie has received services in public schools since she was one year old. This year, for the first time, she has been mainstreamed into a regular first grade class for part of the day. We have visited the school several times to discuss problems that the teachers are having with her, but her loud vocalizations have never been an issue.

D.T., Texas

# Familiar Faces



Nicholas Tietie, 10. shares the first spin around the block on his new bike with sister Emily, 5. Nicholas, a fifth-grader at Byron Elementary School in Tualatin, Oregon, has cerebral paley.



"It's for you, Sis!" Eighteen-month-old Victoria Price of Spring Lake Park, Minnesota loves "talking" on her play telephone with a little help from big brother and best buddy Justin. Mom Laura writes, "Thanks for the opportunity to share my children with others who understand that children are beautiful even if they need extra equipment or their eyes cross."



Three and a helf-year-old Timothy Alexander Crews died last year, shortly after Christmas. "Alex," who had centronuclear myopathy, loved listening to music, riding in the van, wheeling around in his wheelchair and anuggling with Mr. Panda. He communicated fluently using sign language and attended an Easter Seal Society preschool near his home in Mobile, Alabams. His mom, Beverly, remembers Alex as "a bright and heapy child who touched many people."

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!



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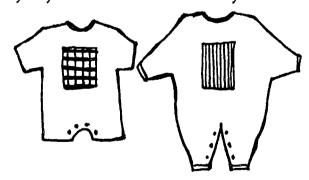
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# One Day at a Time

A family learns to live with epilepsy

by Katharine Byers

he day started like most Saturdays with Clark jumping into our bed for a brief snuggle before watching "Bucky O'Hare." It ended in the intensive care unit with Clark on a ventilator, physically exhausted from his first seizure since infancy. Our seven years as parents had not prepared us for the change this event would bring to our lives.

After breakfast, Clark and I had set off on errands—to the library for new books, to the nursery to get marigolds for the garden, to the mall to find a blue dress shirt for Clark to wear in his role as narrator of next week's kindergarten production of "The Three Little Pigs." It was hectic but fun as we discussed upcoming T-ball games and school activities as we drove. Back at home, Clark seemed quiet and subdued. When he said he was not hungry for dinner, I knew something was wrong. I felt his forehead. He was burning up with fever!

After a cool bath and Tylenol, he lay down for a nap

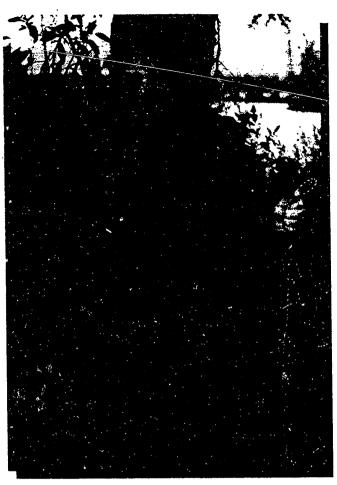
on our bed. An hour later, his fever had come down. As I turned him over to

carry him to his own bed, he started jerking violently, first on his right side and then his whole body. I knew it was a seizure and shouted to Jim to call 911. I cradled Clark as the jerking continued. His head and eyes turned to the side. He started smacking his lips and his breathing became shallow. I kept talking to him, "Clark, it's going to be OK. The ambulance is coming. Just keep breathing. Relax, honey. Relax. It's OK." I'm not sure if my words were meant to reassure him or me.

### A trip to the ICU

The ambulance seemed to take forever, and Clark was still actively seizing when the EMTs arrived. Jim and I answered their questions and gave a short version of Clark's complicated medical history—prematurity, necrotizing enterocolitis requiring the removal of a substantial portion of his intestines, mild cerebral palsy, asthma. It was the first of several times that evening we would recite the litany of his medications and major surgeries. In shock, we reacted calmly, automatically, trying to help without getting in the way of the EMTs.

GRADUALLY WE
REALIZED THAT CLARK'S
fIRST SEIZURE WAS NOT
AN ISOLATED EVENT,
BUT THE BEGINNING OF
A NEW CHALLENGE.



Clark, 10, shows off the whitefish he caught at Squanga Lake during a family camping trip to the Yukon last summer.

The trip to the hospital in the ambulance was like being under water in slow motion. I kept thinking my watch had stopped as I glanced at it every minute. Why was it taking so long when the speedometer said we were going 40 mph? By the time we arrived, Clark had stopped breathing and the EMTs were puffing air into his lungs. After we recited his medical history for the emergency room doctor, Jim and I sat on the couch in the waiting room, holding hands.

Turning to Jim, I said, "I know this may be premature,

but I need to say this: Are we in agreement about no heroic measures?"

"Yes," he said quietly, and squeezed my hand.

The social worker returned with coffee, and we talked while waiting for the medical team to try to stop Clark's seizure and stabilize his condition. More than an hour later, we were allowed to see him.

Sedated from all the medication it



į.

### One Day at a Time

had taken to stop the status epilepticus, Clark was too exhausted to breathe on his own. He remained on a ventilator overnight with us by his side. We watched anxiously, alert for any indication of possible brain damage from such a prolonged seizure. When he started breathing on his own and asking for food, we knew he was better. Several days later, he came home with a diagnosis of an atypical febrile seizure and a prescription for Depakote.



A new challenge

Life quickly returned to normal. There were no more seizures over the summer, and we began to relax. But in the fall, Clark started having seizures again, always in the mornings, but never again associated with a high fever. There were more calls to 911 when his then-diagnosed focal seizures generalized and impaired his breathing. There were more hospital stays, changes in medication, EEGs and visits to the neurologist.

Gradually, we realized that Clark's first seizure was not an isolated event, but the beginning of a new challenge. Clark

had a seizure disorder, and epilepsy does not go away. It took a while for us to be able to say "epilepsy" out loud, with the conviction to fight the stigma still attached to this disability.

### "Seizures stink like poo-poo!"

Nothing in my professional career as a social worker or in my work with parents of children with developmental disabilities had prepared me to live with epilepsy. Nothing in our previous experience with

Clark had prepared us for the anxiety of constantly being on alert. We had survived his premature birth and the worries of his first critical illness when he was given a 40/60 chance of survival. We had dealt with tube feedings when he lost his suck reflex. We had adjusted to mist treatments to keep his asthma under control. We had become accustomed to at least one hospitalization a year and frequent visits to the pediatrician during the cold winter months. We had gotten used to ongoing physical and occupational therapy to counter the effects of his mild cerebral palsy.





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Now we had a new label, a new medical specialty, new tests and new medicines to learn about. I knew I would like Clark's first neurologist when he wore a Mickey Mouse T-shirt at our first meeting in the hospital. The book he recommended provided helpful information but also added to our anxiety when we learned that controlling seizures was more trial and error than exact science. Learning that Clark's seizures might get worse before they got better made us feel we were on an out-of-control roller coaster. Learning that children who have seizures often have learning problems was devastating.

We were angry, confused and worried, and when we took the time to listen, so was Clark. During one early visit to the neurologist, he said angrily, "Seizures stink like poo-poo!" and the doctor agreed. Clark understood more than we first gave him credit for; we have since learned to talk to each other about our feelings. Only if we accept the anger and lack of control we sometimes feel, can we move to exert what control we can.

### One day at a time

As a family, we are learning to live with epilepsy. It has been five years since Clark's first frightening seizure, and he has been seizure-free for more than two years. Still, school personnel, parents of friends and Clark all know what to do in case a seizure begins. Clark reminds us

when it is time to take his Dilantin, and we make sure he gets enough rest.

We have learned not to let the possibility of seizures define our lives or Clark's. We are cautious, but allow him to participate in normal 10-year-old activities—Boys' Club basketball, sleepovers, swimming in the pool. We took a long-anticipated camping trip to the Yukon last summer.

Clark is not an "epileptic;" he is a young man who has seizures. He has successfully confronted situations many adults have never had to face. Though mature beyond his years in many ways, we are determined that seizures will not rob him of as normal a childhood as possible. We are learning to live one day at a time, to enjoy each day fully and completely, and to stop putting important family activities off because we can never predict with certainty what tomorrow will bring. **EP** 

Katharine Byers lives in Bloomington, Indiana with 10-year-old Clark, and Jim, her husband of 25 years. Kathy has administrative and teaching responsibilities in the undergraduate social work program at the Indiana University School of Social Work. She is active in the National Association of Social Workers and serves on the Advisory Board of the Institute for the Study of Developmental Disabilities.

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# Mobility—"The devil is in the details"

he purchase of mobility equipment for a family member with a disability is sometimes compared to the purchase of an automobile. This comparison is not particularly helpful because of the vast differences in industry economics, available choices and the degree to which the consumer is dependent on the product for day-to-day life.

A car buyer can choose to purchase an automobile from one of many companies offering a variety of products at a wide range of prices. It is relatively easy to become informed—a great deal of information is readily available from both automobile manufacturers and independent sources. A car buyer also has some choices about how to pay for the purchase. Or if the consumer doesn't want to buy a car, leasing is an option. Some consumers may decide that a used car is sufficient for their needs. Or, particularly in urban areas, a consumer can

decide to forego automobile ownership and make use of public transportation.

The consumer with a disability who needs mobility products (wheelchairs. lifts, vans and ramps) does not have the same kinds of choices. To begin with, he or she cannot decide to go without mobility equipment. Even though public transportation options for people with disabilities are expanding, the individual still needs at least one wheelchair, stroller or scooter. While there are many wheelchair choices for the consumer, there are few financial options. Usually, a new wheelchair is purchased by the consumer or a third party. The consumer rarely has the opportunity to purchase a used wheelchair, to lease a new or used product or to finance a purchase over time. And, unlike automobiles, wheelchairs are rarely resold and cannot be "traded in" on a new one. Finally, in terms of actual dollars, the price of a new powered wheelchair or scooter for an individual with a disability may exceed the price of an automobile that transports an entire family.

These factors and others lead to a complex relationship between consumers, manufacturers and retail distributors of mobility products. To most consumers, prices seem too high. At the same time, many manufacturers and retailers struggle for financial survival.

### **Manufacturers**

I have met many manufacturers of mobility products since *Exceptional Parent* began in 1971. When a parent of a child who needed a wheelchair explained the need for consumers like himself to have access to advertisements and other information about products, the magazine began to actively solicit product advertising. Over the years, we have learned the

### "Hop On!"

Our daughter, Stephanie, was diagnosed with Werdnig-Hoffman disease at 16 months of age. This neuromuscular disease weakens her arms, legs and torso, severely impairing her mobility.

Stephanie is a very bright child. We felt that independent mobility and socialization were very important. With the help of her physical therapist, we pursued a motorized wheelchair.

When Stephanie was 21 months old, one of her doctors told us that she was too young to operate a motorized chair. Using a "loaner" chair, Stephanie showed her how easy it was. We were also told that the insurance would never approve it. Well, it took a while, but she received her wheelchair when she was two years old.

Stephanie is four years old now. The last two years have been wonderful for all of us. We enjoy seeing Stephanie explore her environment and test her boundaries. She is able to participate in activities with her typical peers. She likes to tell the neighborhood kids to "hop on" the back of her chair for a cruise up and down the block.

There have been some drawbacks. For example, we

now have less control over her. When she is in a defiant mood, she "runs away" from us.

One time when we picked her up from preschool; her teacher told us that Stephanie got a time-out for running over a teacher. The teacher had leaned over to tie her shoe and Stephanie couldn't resist the target.

Last year, Stephanie went trick-or-treating in "wet" weather and short-circuited her wheel-chair. She "shorted" her chair again, by going through the sprinkler at the private preschool she attends. It has all been worth it though, to see her interact with other children. We wanted

her to be just like her peers without disabilities, and she is.

Last May, Stephanie was the flower girl in her aunt's wedding. She drove down the isle proudly and participated in the entire ceremony. She did such a good job that she has been asked to be the flower girl in another wedding next August.

Even though we realize Stephanie will always have some limitations, we want to help her develop a sense of independence and the knowledge that she can continue to be successful at her own rate.

—Sharon Royster Hudson, Ohio



value of responsible advertising to parents and professionals.

Most of the manufacturers I have met became interested in this field as the result of a personal or family need. Often starting on a kitchen table, or in a basement or garage, individuals slowly created businesses. With talent, creativity and dedication,

some individuals have built successful businesses; a few have built large corporate enterprises. It is not my intention to glamorize individuals or companies or apologize for the cost of products. Rather, I want readers to know that most of the manufacturers I have met over the years are responsible, caring people who want to

improve people's lives. At the same time, these individuals also want to make a living.

### Consumer input

In preparing this issue, we invited comments from manufacturers about how users, parents ar d professionals can make their ide is and opinions known to product manufacturers. Manufacturers told us they welcome input because they need to know whether they are meeting customers' needs and want help in improving and refining products. However, manufacturers reminded us that new product development is a slow and costly process and that "the devil is in the details." A wonderful idea may take a long time to be transformed into a viable product.

Some manufacturers send out questionnaires, hold focus groups and solicit feedback at meetings of professionals and consumers. All asked me to convey to our readers that they welcome ideas and suggestions. In fact, most suggested that top management individuals within these companies were eager to hear feedback directly from parents and professionals.

Rehabilitation engineering centers at universities and hospitals can also play a role in product development. Parents and professionals can discuss ideas and questions with experts in these settings. We received a number of examples of this process and have included one in this issue (See "Kyle's New Bike," page 38). When there seems to be a sufficient market, the products developed at these centers may become commercially available.

One of our goals in this issue is to explain the different roles of the individuals involved in mobility decisions so consumers and professionals can be well-informed as they consider possible choices. At the same time, we have illustrated the complexity of the process and the need for comprehensive assessment of a user's needs before decisions are made. The process is not an easy one, and it cannot be "simplified."

-S.D.K.

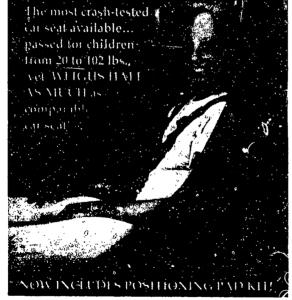
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# **Obtaining Specialized Equipment**

Who's who in the process

by Adrienne Falk Bergen

here is an evergrowing amount of specialized equipment available for children with special needs. The challenge lies in selecting the most appropriate product. How do you choose the right piece(s)? Who can help the family through the maze?

The process of obtaining specialized equipment always begins the same way—someone notices that a problem exists. It may be a child who is uncomfortable or sits poorly, or equipment that no longer meets the child's needs. If a caregiver, family member or teacher is the first to recognize a problem, they should report it to the

child's primary therapist. If the family is not aware of the problem, they should be notified first. For a child who is not receiving ongoing therapy, the problem should be reported to the person or facility that manages the child's equipment needs.

If the child's primary therapist receives a report of a problem, he or she can usually decide if it can be solved on-site with simple adjustments using available tools. If not, the therapist may call a team meeting, approach the equipment supplier for suggestions or refer the child to the medical clinic that manages his or her equipment needs.

Even if the therapist refers the child to another site, it is important that he or she be involved in the assessment process so the recommended equipment is appropriate for reinforcing the child's therapy goals. The child's primary therapist and the child's family are the experts on the child's daily life and his or her living and learning environments. The person doing the assessment may see the child in an unfamiliar setting for a relatively brief visit. Involving the child's family and primary therapist(s) in the assessment process may take extra time, but using input from varied sources leads to a better result.

continued on page 26

### A Black Tie Affair

When Todd was 13, he celebrated the arrival of his new chair by renting a tuxedo—without even telling us—to wear on his first day using the chair. He was so proud. He wanted to show it to the world and especially to all his friends at the Summit Mall in Akron, Ohio, where his dad owns a tobacco store.

Since Todd was 10, his dad has been letting him roam

Todd Carson, then 13, rented a tuxedo to celebrate the arrival of his new wheelchair.

nas been letting nim roam the mall. He began by visiting the store next to his dad's. He gradually made his way around the whole mall. He has friends everywhere who watch out for him, so potential dangers have been minimized. Todd even bought a popcorn machine and earns spending money by selling popcorn and running errands, such as delivering lunch to clerks stuck in their stores all day.

While Todd, now 16, has multiple disabilities due to a grade IV intraventricular hemorrhage shortly after birth, he is

very aware and extremely verbal. He enjoys discussing sports statistics with the guys at the tobacco shop. After getting to know Todd, people see past the wheelchair and discover the unique person.

Todd's wheelchair has allowed him to enjoy base-ball games, basketball games and wrestling tournaments. He has "danced" all night at a sorority-sponsored dance marathon at the mall to earn money for charity. He makes "dates" with special friends and takes them out to lunch at the mall with money earned from his popcorn sales. He has participated in the Special Olympics and won first place for Frisbee throw and wheelchair slalom.

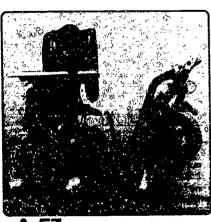
The wheelchair lets Todd be one of the kids on the block, riding up and down the street or pulling his little brother in his wagon. He has felt useful by hauling branches when the family does yard work. He has taken off by himself down a rugged path in northern Canada where we go camping—with me watching over him by jumping behind trees.

Todd's wheelchair has given him an incredible sense of independence. To someone who must depend on people for every other need, such as feeding, dressing and toileting, having one area of your life where you're in control means the world. No wonder Todd's last words every night are "Did you plug in my chair?"

—Jean Carson Clinton, Ohio



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continued from page 25

### Who's who?

It is important for everyone to understand the roles of the various people involved in the problem-identification, assessment and equipment-provision process. This will help each team member know where to go for the information they need along the way. The sidebars to this article, "Our Child Needs a Bath Chair" and "Our Child Needs a Wheelchair and Seating System" illustrate how parents and professionals work together to purchase mobility equipment.

- User: The person who actually uses the equipment.
- Family: Parents, grandparents, siblings, legal guardian and/or significant others who are directly related to the user of the equipment.
- Caregivers: Family members, friends, nurses, aides or paraprofessionals who give direct care to the user in any environment.
- Teachers: Educators involved with the user.
- Treating therapist(s): Physical therapist, occupational therapist or speech pathologist who assesses the needs of the user, formulates goals and provides or prescribes treatment interventions to meet those goals. Therapists may work with the user at school, at home or in a clinic.



Robbie Shauer (center) tries out a seating system surrounded by team members (from !eft) physical therapist Linda Cimino, Robbie's mom, occupational therapist Stephanie Welson and rehabilitation technology supplier Faith Safter, P.T.

The treating therapist may not know enough about the various types of currently avail-

able equipment to make a recommendation. In this case, the therapist may refer the child to another qualified professional for actual recommendations. The treating therapist must collaborate with the assistive technology assessment team to ensure they have accurate and up-to-date information about the user, including past history, present goals and problems, and the reason for the referral. Some treating therapists have additional expertise in the area of specialized equipment, and can also serve as the child's assistive technology practitioner (see below).

• Assistive technology practitioner (ATP): Sometimes called an adaptive equipment specialist, the ATP is usually a physical or occupational therapist who specializes in assessing clients for specialized equipment and can assist the treating therapist in meeting treatment goals through the use of adaptive equipment. In most areas, these professionals can be found in wheelchair clinics or schools for children who are technology-dependent.

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The ATP is a resource for the child, the family and the treating therapist. He or she also acts as team coordinator—arranging for assessment visits and product trials, preparing supportive documentation, ensuring that recommendations reach the proper physician(s) and making sure that all materials needed for funding submissions are completed in a timely fashion. As coordinator, the ATP facilitates all interactions with the rehabilitation technology supplier, arranges for fittings and deliveries, and follows up

on any problems that arise during the process.

• Rehabilitation technology supplier (RTS): Formerly called an equipment dealer or vendor, sometimes still called a durable medical equipment supplier, this person works for a local company that supplies durable (i.e., not disposable) medical equipment. The RTS has special expertise and experience to assist the clinical team in the hands-on assessment process and is knowledgeable about the types of com-

mercially-available equipment. The RTS will also be knowledgeable about possible custom (individualized) modifications to existing equipment, creating certain types of equipment from raw materials (called fabrication).

The RTS can provide information on prices and funding. He or she should offer the team a menu of choices for discussion, provide equipment for product trials and be available for assessments, interim fittings and delivery. The RTS usually works for a company that can provide support services (i.e., repairs and maintenance) to users.

• Manufacturer: The manufacturer is the company that actually makes the piece of equipment.

Manufacturers must follow strict regulations developed and enforced by the Food and Drug Administration (FDA). Some rehabilitation technology suppliers create seating systems "in house," but are rightfully termed "fabricators," not "manufacturers." Some manufacturers sell directly to consumers, but most require that the consumer make purchases through a rehabilitation technology supplier. This allows the manufacturer to be sure the equipment is being supplied appropriately, and that the consumer will have a local source for service and repairs.

• Manufacturer's representative: This person may work directly for a manufacturer or be an independent representative for several manufacturers. "Reps" usually serve a specific geographic "territory" and work directly with rehabilitation technology suppliers in their territory—providing equipment for trials, giving presentations about the use of their equipment and troubleshooting when problems arise with the manufacturer or when a consumer has a special need.

The representative has a vested interest in the products they represent. Their incomes are based on the amount of equipment ordered from the company they represent through the rehabilitation technology suppliers in their territory. Representatives

continued on page 30

### **Our Child Needs a Bath Chair**

The TREATING THERAPIST speaks to the FAMILY to discuss their goals for this piece of equipment. The THERAPIST may do a home visit to determine the type of equipment that might work best for the USER in her home environment.

### OPTION #1

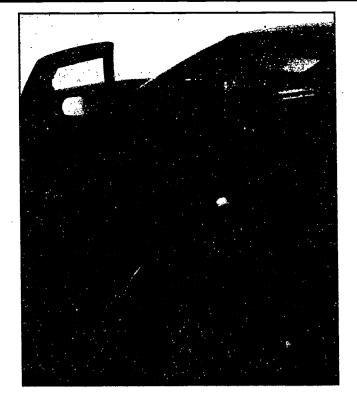
The family plans to pay for the bath chair initially. The case manager at their health insurance company tells them they may submit for reimbursement from the company—the payer—after the fact. The treating therapist and the family look through catalogs from various distributors and some manufacturers who sell direct. They choose an appropriate chair and place an order. The chair is shipped to the family from the distributor or manufacturer. The family and therapist read the instructions and learn to use the equipment properly. If any problems arise with the chair, the family will have to deal directly with the distributor/manufacturer.

### OPTION #2

The treating therapist calls an RTS who helps the therapist and the family select a product. The RTS may obtain sample bath chairs for the child to try from the manufacturer or the local manufacturer's representative. The RTS provides a price quote and submits it to the payer for prior authorization. When the equipment arrives, the RTS, or someone from his or her company, will assemble it, deliver it and demonstrate its use. If any problems arise with the chair, the RTS will deal with the manufacturer on the family's behalf.

### **OPTION #3**

The treating therapist, who is not familiar with the full range of available bath equipment, contacts an ATP who works at the equipment clinic where the child's previous equipment needs have been evaluated. The therapist and ATP discuss the child's needs and therapy goals and, with the family, select an appropriate chair. The family can then order the chair from a distributor (See Option #1) or through an RTS (See Option #2). To facilitate funding of this purchase, the ATP can assist with processing insurance forms and can provide a letter of medical necessity for the payer.







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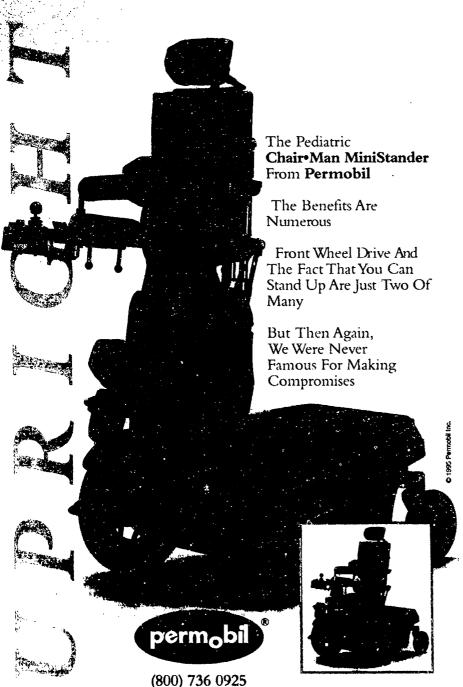


### Our Child Needs a Wheelchair and Seating System

The family deals with a combination of payers, or funding sources, including private insurance and Medicaid. The private insurance company has a list of preferred providers, but these providers are all home medical equipment suppliers, none of which have an RTS on staff.

The insurance company's case manager gives the family permission to seek a supplier outside of their regular network. The family asks the treating therapist if the child might be a good candidate for a power wheelchair. The therapist calls the ATP and discusses the issue. The child goes to the wheelchair clinic, either with or without the treating therapist, for an initial evaluation.

After obtaining all the necessary information about the child's abilities and goals and the environment in which the chair will be used, the ATP makes arrangements with the assigned RTS or a manufacturer's representative to have a power chair delivered to the child's school for a product trial. Once a product decision is made, the ATP facilitates its purchase and funding as described in Option #3 in the bath chair example.



continued from page 28

may not know about or suggest products from other manufacturers, even if they might be more suitable for an individual user.

- Distributor: This person gathers equipment manufactured by many different companies and offers it for sale. They may also manufacture some equipment. Distributors usually can provide a catalog. Consumers may buy directly from the distributors or go through their local RTS. The RTS may charge a higher price for the same equipment to cover the costs for obtaining it from the manufacturer.
- Payer: The payer is the source for funding for the equipment—usually a private health insurance carrier or Medicaid (which can be used only after other available funding sources have been exhausted or if a child has no other health insurance).

Some insurance carriers have "preferred providers." To receive full reimbursement, consumers with this type of coverage must obtain equipment from a specific provider on the insurance company's list. However, most insurance companies will make exceptions if listed companies cannot provide the type of equipment being prescribed. EP

Adrienne Falk Bergen, P.T. has been a physical therapist for 25 years. She worked for 15 years at Blythedale Children's Hospital in Valhalla, New York. For the last 10 years, she has worked as a rehabilitation technology supplier with Dynamic Medical Equipment in Westbury, New York. Adrienne is a past chairperson of the National Registry of Rehabilitation Technology Suppliers (NRRTS). She lives in Valhalla, New York with her sons, David and Justin, and husband, Barry.

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Circle #206

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### Finding a Rehabilitation Technology Supplier

Many rehabilitation technology suppliers are skilled in providing specialized wheelchairs, walkers and other mobility devices for children and young adults with disabilities. But how can parents avoid those few suppliers who are incompetent or downright unethical?

Your child's doctors or therapists may refer you to a qualified rehabilitation technology supplier. Parents of children who use similar equipment can be another excellent resource. Local disability service organizations may also be able to make suggestions.

Professional organizations can also make referrals:

• The National Registry of Rehabilitation Technology Suppliers (NRRTS) is a nationwide organization of more than 250 members. Members must have demonstrated competence through experience and education. They are also required to sign a code of ethical conduct and obtain recommendations from local health care professionals. NRRTS, 3223 South Loop 289, Ste 600, Lubbock, TX 79423, (806) 797-7299 (voice), (806) 797-4820 (fax).

• The MED Group is a nationwide network of independently-owned-and-operated rehabilitation and home medical equipment retailers and repair centers. The MED group certifies technicians who repair wheelchairs.

The MED Group, 3223 South Loop 289, Ste 600, Lubbock, TX 79423, (800) 477-6272 (voice), (806) 793-6480 (fax).

• **RESNA** is a professional organization supporting the use and development of assistive technology. Currently, RESNA is forming a quality assurance program for rehabilitation engineers and other professionals.

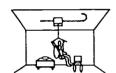
RESNA, 1700 N Moore St, Ste 1540, Arlington, VA 22209, (703) 524-6686 (voice), (703) 524-6639 (TTY), (703) 524-6630 (fax).

• National Association of Medical Equipment Services (NAMES) represents more than 2,000 home medical equipment and rehabilitation technology suppliers. NAMES, 625 Slaters Ln, Alexandria, VA 22314-1176, (703) 836-6263 (voice), (703) 836-6730 (fax).

• The Joint Commission on Accreditation of Health Care Organizations develops standards and accredits organizations in all areas of health care. Joint Commission on Accreditation of Health Care Organizations, One Renalssance Blvd, Oakbrook, IL. 60181, (708) 916-5800 (voice).

-Dan Lipka

Dan Lipka, M.Ed., is a licensed occupational therapist and an adaptive seating and mobility specialist with Miller's Adaptive Technologies in Akron. Ohio. He is the vice president of NRRTS.



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Circle #39



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# **Powered Mobility?**

Making an informed decision

by Phil Reppert

arents frequently ask whether or not to introduce a powered wheelchair to their child. The question is phrased in many different ways: Will my child still want to walk if she receives a powered wheelchair? Will my child's arms become weaker if he uses a powered wheelchair instead of pushing a manual wheelchair? Will my child become lazy? Is my child too young?

A child's therapist or physician may express a strong opinion for or against powered mobility. Many times, two therapists will have opposing opinions.

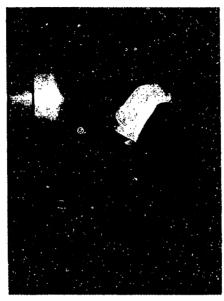
There is no single "right" answer to a parent's question about powered mobility. Each child is different. Each family is different. Each home, community, school and job is different. However, by developing mobility goals and a plan of action with a child's therapists, the family can make a more informed decision based on their needs and values.

### Sonia's story

Sonia Quijano, 16, is a high school student with cerebral palsy. She began receiving ongoing therapeutic services at age five. Each year, her therapists established goals for her to push her manual wheelchair and walk with bracing. But at age 13, Sonia still did not have a useful form of mobility that allowed her to keep up with her peers.

At that time, her therapists decided to spend six months documenting Sonia's ability to use three forms of mobility—walking, manual wheelchair pushing and powered mobility. The goal was to discover the form of mobility that would allow Sonia to move at the same speed and for the same distances as her peers.

After testing her standing and walking ability, it was determined that walking would not meet her daily mobility needs. Standing and walking remained a part of her therapeutic program in



Sonia Quijano, 16, received her first powered wheelchair when she was 13.

order to facilitate her ability to transfer (for example, from chair to toilet) and possibly walk with assistance for short distances.

At the time of her evaluation, Sonia had the ability to push her manual wheelchair slowly. When she attempted to propel her wheelchair quickly, she could maintain the speed for only a short distance. Sonia's therapists established as a goal that she would improve her ability to push her manual wheelchair, increasing speed and distance, moving up and down ramps and maneuvering the chair in tight spaces. Therapists encouraged Sonia and her classroom staff to let Sonia push the chair independently.

Sonia's therapists measured speed and distance before and at the end of the six-month period. There were small improvements in her ability to push the manual wheelchair faster over longer distances. However, she was still being pushed by others, particularly when she had to be somewhere within a specific time period. Sonia continued to lag far behind her classmates when moving to different locations within the school.

After the manual wheelchair training period, Sonia was introduced to a joystick-controlled power wheelchair. Within a few days she was fully independent. Using a fraction of the energy required to push her manual wheelchair, Sonia was able to go anywhere in the school. Her heart rate was significantly lower than when she was pushing her manual wheelchair. Timing the speed at which she traveled specific distances within the school, her therapists found the powered wheelchair to be about three and a half times faster than her manual chair. In the powered chair, Sonia sought out and initiated social contacts, rather than sitting passively in the same place.

After these trial periods, Sonia and her mother agreed with the therapists that a powered chair was the only way for her to move at the same speed and distance as her peers. Her therapists used their documented observations of Sonia's increased independent mobility, along with issues of safety, greater vocational choice and less caregiver supervision and responsibility, to gain approval for the prescription and funding of Sonia's new powered chair.

### An informed decision

Here are suggestions for parents to make an informed decision about powered mobility with their child's therapists and other team members:

• Develop mobility goals and a plan

• Develop mobility goals and a plan of action with your child's therapists. Along with your child, list daily activities that are important for your child to perform at home, at school and in the community. Home goals may be to travel independently several city blocks to a local playground or grocery store, or to move around the backyard while playing with siblings.

Go to your child's school and observe the daily activities your child participates in with peers. A school goal may be for the child to move independently at the same speed and for the same distances as classmates during all school activities.

Together with your child and team members, develop a plan of action to determine the method(s) of mobility that may allow your child to meet these goals. Should an intense period of physical therapy concentrate on a child's walking ability? Should an effort be made to develop the child's pushing skills in a manual wheelchair? Should the child immediately begin training with a powered wheelchair? Should he or she develop walking skills for short distances and learn to use a powered wheelchair for activities that involve traveling longer distances?

Whatever the plan of action, set time limits with therapists to assess whether or not your child is developing the skills required to meet the mobility goals. If a child is not benefiting from the current plan of action, valuable

time can be lost.

- Have your child try a powered wheelchair: Have your therapist help you and your child obtain a powered wheelchair for trial use. Many times, the advantages and disadvantages of a powered wheelchair are not recognized until the child actually tries the device. Having a child try using a powered wheelchair in his natural environment—such as school—can provide parents, therapists and educators with valuable information about his ability to use the chair safely and responsibly.
- Make your therapists accountable for the information they are providing to you. Your therapist may have a very strong opinion about whether or not your child should use a powered wheelchair. A therapist may suggest that if a child begins to use a motorized

wheelchair, he will lose all desire to walk. Likewise, another therapist may indicate that if a child can move independently in a powered wheelchair, his desire to move and walk will increase. Ask therapists to provide you with documented cases or research that supports their opinions.

• Talk to other parents and children who have dealt with the same questions about powered mobility. Sometimes, the best resource is other parents. Ask your therapist to put you in touch with other parents who have dealt with similar questions and decisions. **EP** 

Phil Reppert is a physical therapist working with children and young adults in the New York City public schools.

### A Larger View of the World

ur nine-year-old son Danny was born prematurely with complications arising from a group B strep infection. Oxygen deprivation resulted in permanent brain damage that left him unable to walk independently, unable to sit for long periods and only able to use his right arm and hand for functional tasks. He has some visual-perceptual difficulty, but above-average intelligence.

When Danny was three, we began to notice that his lack of independent mobility was adversely affecting his development because he was not able to see and experience the world like a child who is mobile. His view was from his highchair or the floor.

Although Danny's occupational therapist recommended a power wheelchair, we were reluctant because we felt he could make progress with a walker. We wanted to "force" him to go as far as he could, hoping he would become a "walker."

We agonized over this decision, but finally ordered his first chair—on his fourth birthday—based on three factors. First, Danny was getting bigger and more difficult to handle at home and at the regular nursery school he was attending. Second, we wanted to make sure he developed at an appropriate

Danny won the "Most Patriotic Float" award at a neighborhood Fourth of July parade last year.

rate. Third, his physical therapist told us that "sometimes it is better to have a happy wheelchair user than an unhappy walker."

Now a third-grader, Danny has been in a regular class at our neighborhood school since kindergarten, except for first grade, where he was placed in a self-contained learning disabilities class where he made little progress. He is now pulled out of class for physical and occupational therapy sessions and receives individual and small-group tutoring in reading and math.

Being in the regular class has been a very positive experience for Danny, his teachers and the other

children. We have seen him grow in independence, class participation and maturity. And he has lots of friends without disabilities from school, church and our neighborhood. He loves to play cops and robbers at recess and is able to keep up with the other kids in his power wheelchair.

Safety was a big concern for us. But we feel comfortable letting him zoom around the neighborhood with his seven-year-old sister. He can even use his chair to explore the woods behind our home.

Danny's full inclusion in the community would have been difficult without independent power mobility.

> ---Dan and Margie Wright Hudson, Ohio





** 242

# **Controls for Power Wheelchairs**

Choosing the most appropriate control

by Peggy Barker

ower mobility can be considered for many children even if they cannot use a hand-controlled joystick. A child's physical abilities can be matched to the characteristics of available controls (See sidebar: "Control Options for Power Wheelchairs," page 36). Before beginning this process, it is important that the child is securely and comfortably positioned. (See "Proper Seating and Positioning," February 1995).

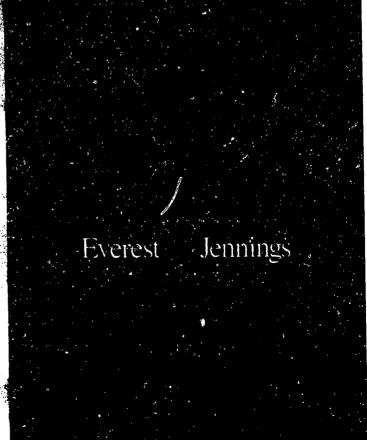
Once positioned, the child should be able to work with each potentially useful control, with supervision, until the evaluator determines whether that control is effective. Proportional controls should be considered first because they provide fine control. Switch arrays should be considered next. A single switch with scanning should be considered as a last resort; scanning systems require extra time because the user must wait for all possible activation choices to be scanned before he or she can choose a function.

For many children, a two- or three-hour trial will not be

sufficient. It may require several weeks to become accustomed to operating the control while the chair is moving. A rental program that includes power wheelchairs of different sizes, with various positioning components and a variety of control options, can be used to give a child more time to practice with the control and to experience power mobility. The rental program should give the child two weeks to three months to work with the equipment. A rental can also allow the child's family and teachers to evaluate the chair at school and home. A follow-up evaluation is needed to determine whether the child can learn to operate the power mobility system safely, and if so, to justify its purchase for funding agencies.

A child's ability to use a power wheelchair should continue to be re-evaluated on a regular basis. As children grow and mature, their physical control and potential to safely and effectively operate a power wheelchair usually improves. **EP** 

park, and pondered the panthers and pythons, then probed along the surface of Mars in their trusty all-terrain vehicles. They've recovered the last of the golden keys while their computer proclaims them heirs to the realm. Kid PowerTM is for kids making tracks. A child's tool, like a child's toy must be durable and adaptable, allowing them the freedom and range to explore their environment creatively and independently. Kid PowerTM is tough and reliable with a unique styling that adjusts to your child's changing needs. Kid PowerTM is easy to program, with precision controls, accessible battery boxes, controlled tracking, a rugged steel frame and a host of options that allow kids to assert their individuality and lifestyle.





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# **Control Options for Power Wheelchairs**

• Proportional controls (used for incremental control of direction and speed) include hand-, head- or foot-controlled joysticks, or

"shortthrow" joysticks that require less movement to reach the chair's maximum speed. • Non-pro-



Proportional headcontrolled joystick.

portional controls (used to just turn a function, like direction or a certain speed, on or off) include contact switches activated by a press or a touch, proximity switches activated by the user's physical closeness, puff-sip switches or a single switch with scanning of all directions that may be used to activate all the functions of the chair.







#1: Contact switches: an array of three diec switches on

an adjustable mounting bracket. #2: Scanning array: an array of scanning lights is used to select the direction the wheelchair will move. A single switch is used to stop the scanning at the chosen function. #3: Proximity switches: three switches imbedded in a headrest are activated by the user moving his or her head closer to the headrest.

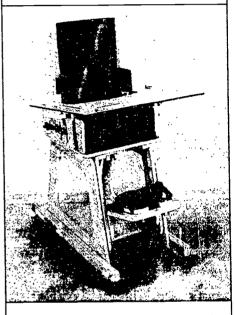
Peggy Barker, M.S., is a rehabilitation engineer working as an independent consultant. She previously was the communication/control service chief at Packard Children's Hospital, Stanford Rehabilitation Engineering Centur in Palo Alto, California.

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# The Art of Manual Wheelchair Maintenance

by Mary Angelico

ike changing the oil in your car, manual wheelchair maintenance can be relatively easy and inexpensive. Poor wheelchair maintenance can lead to expensive repairs, discomfort and a loss of function.

In many cases, older children can learn to be responsible for their chairs by doing routine chair care and scheduling professional maintenance appointments.

Keeping the wheelchair as clean as possible is probably the easiest and most effective way to prevent wheelchair breakdown. Routine care includes:

- · Wiping down spills as soon as possible.
- Cleaning out cracks and crevices where crumbs and dust collect.
- Washing and air drying cushion covers, on a weekly basis if necessary.

The following are guidelines for maintenance to be done every two months. This schedule may vary depending on ways the wheelchair is used. Develop the best maintenance schedule for your needs with your rehabilitation technology supplier (RTS).

### Seating system

If your cushion is made from Naugahyde, which is not 100 percent waterproof, it can be wiped down with a sponge and

warm, soapy water (using a mild dish detergent) and then dried immediately.

If your cushion has a removable cover made from nylon or Lycra, follow the manufacturer's washing instructions precisely, or wash the cover using Woolite and cold water; then hang it to dry. With the cover removed, wipe the cushion with a damp rag without soap.

If your cushion's cover is not removable, you can clean it with warm, soapy water and a soft-bristled brush. Use as little water as possible, and soak up excess water with a dry cloth. Air dry or use a cool blow dryer only. Once

continued on page 40

### Kyle's New Bike

Larms and both legs to amput ion before the age of two, he never lost his enthusiasm for life and his desire for independence. His family made sure of that.

Surgeons amputated his arms above the elbows and took two thirds of both legs because a rare disease, meningococcemia, damaged his circulation, caused gangrene, and almost took his life.

Now an energetic seven-year-old, Kyle gets around school in his power chair, rides horses and has been involved in Little League baseball. But there was one thing the Tampa, Florida native always wanted to do but never could—ride a bicycle with his friends.

"I've wanted it since I was four," Kyle says.

He got his wish recently when 11 mechanical engineering students at the University of South Florida (USF) presented him with a specially-designed tricycle he can power and steer on his own.

The tricycle, with two wheels in front and one in the back, was designed and built by the USF students as a class project. It took eight months to complete.

Kyle uses the stub of his right arm to steer the



Kyle Romano tries out his new bike. With him are younger brother Kent and parents Kris and David.

vehicle and the stub of his left arm to shift and brake. He powers his bike by pushing his chest forward against a padded bar and then back. Both motions make the bike move.

"We created a drive arrangement where you convert the rocking motion into a forward rotation of the rear wheel," USF professor Stuart Wilkinson explains. "it's unique."

USF student Brian Corces, who worked on the project, will work with Kyle as part of an independent study program to make any adjustments to the bike, that is, if Kyle stays off it long enough. According to his mother, Kris, the energetic boy rides it almost every day with his friends.

"His friends think it's great that he can power it himself," she says. "They help him when he gets into jams.

They're very supportive."

She also has noticed a change in his self-esteem and spirit.

"He has a new feeling of independence," she said. "Our only trouble is keeping him off of the bike, especially when he has homework... just like any other child."

—Ron Faig University of South Florida, Tampa

### PRODUCT NEWS



### Lightweight Portability Solves Transport Problem

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### New Bus/Van Tie-Down Models

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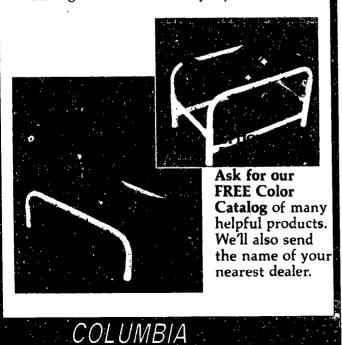


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- The Wrap-around Support (above) lets your child play in the water while seated upright
- The Reclining Bath Chair (below) gives your child full-length head and trunk support; the angle of the seat is easily adjustable



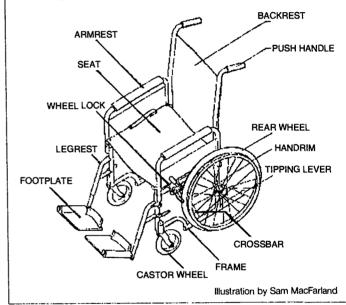
continued from page 38

dry, the cushion can be brushed to soften it up.

The seat pan—the metal or plastic piece that the cushion rests on—can be safely cleaned with a sponge and warm, soapy water. Don't use steel wool pads; they will scratch the surface.

### Frame

The frame of your wheelchair includes the seat rails, the upright cranes and if present, cross braces. Clean these parts with a damp cloth and warm, soapy water. Do not use an abrasive cleanser or steel wool because they will scratch the paint. Grease spots may be removed with a spray cleaner, such as Fantastic or Formula 409. Touch-up paint may be available through your RTS.



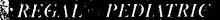
### Wheels

Wheel maintenance includes the tires of the rear wheels, spokes, axles, wheel locks and casters (the front wheels).

- Tires are either solid rubber or filled with air (pneumatic). Check solid tires for wear and tightness to the wheel (there should not be any slack). Worn tires should be replaced before the inner material is exposed. Check pneumatic tires for pressure and for tread wear. If the treads appear less than one centimeter deep, they should be replaced.
- Wheel alignment can be checked by allowing the wheels to rotate freely without touching the floor. (You can check one wheel at a time by turning the chair on its side). If the wheel wobbles when you spin it, it is not properly aligned and requires maintenance by your RTS.
- Check the wheel locks when you check alignment. Engage the locking mechanism and try to turn the wheel. If the wheel moves at all, either the lock or the tire pressure needs adjustment. Ask your RTS for assistance.

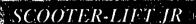
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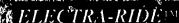


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- To clean dirt and grime from quick release wheels, remove the wheel and scrub the axle with a steel wool pad. Wipe off excess soap and grime with a wet rag, then dry the axle. Re-lubricate the axle using household oil, such as 3-in-1, available at most hardware stores. Clean the hole the axle fits in by pulling a rag through it several times, and re-lubricate it with household oil
- The wheel spokes need to be evenly tightened for proper tire alignment. If a spoke is loose, you can use a spoke tightener to secure it. Both over-tightened and under-tightened spokes affect the ride. If you are uncertain doing this, ask your RTS to do it.
- Casters tend to pick up lint, thread and other debris. Remove this debris from the caster forks and clean the axles in the same manner as the rear wheel axles. Instructions on caster

removal are in the wheelchair booklet supplied by the manufacturer.

### Supports

Position and condition of leg rests, footrests and armrests are critical to comfort and function for the user. If leg rests are removable, check the locking mechanism to see that it works smoothly and easily. After cleaning the entire leg rest and footrest assembly, use household oil to re-lubricate the hinges on the calf pad, footrest and knee hinges. Clean the armrests and, if necessary, the posts they slide into. If there is excessive motion in the armrest and an obvious loose screw, tighten it. If the problems persist, check with your RTS.

### Wheelchair tune-ups

Wheelchairs and their seating systems should have a tune-up-usually called a clean, lube and overhaul-every six

months by your RTS. Tune-ups include replacement of bearings, a complete cleaning, lubrication of all moving parts and a check to make sure all screws are tightened.

Tune-up costs range from \$50-\$100. The cost may include pick-up and delivery of the chair and, if possible, the use of a loaner chair.

Many services may be covered in the chair's warranty. Before paying for any service, be sure you are familiar with your warranty's inclusions and limits. EP

Mary Angelico, P.T. is an assistive technology practitioner in physical therapy in private practice. She has worked for the past nine years in the Chicago area at LaRabida Children's Hospital and the Assistive Technology Unit, Institute on Disability and Human Development at the University of Illinois.



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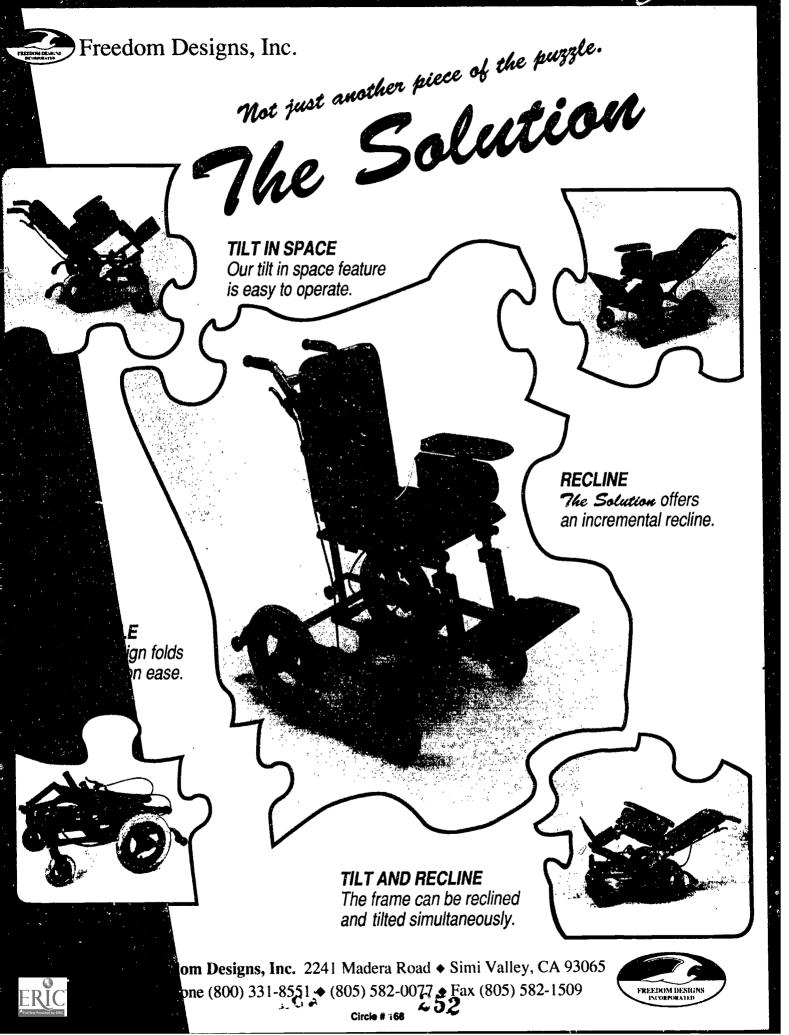
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## **Special Needs in the Lunchroom**

Modifying school meals for students with special eating needs by Gloria Frolek Clark

acos, grapes, carrot sticks, an iced cinnamon roll and milk. Sounds like a typical school lunch, right? Most children have two options—eat hot lunch or bring lunch from home. But what are the options for children who choke on any foods except baby food, easily aspirate liquids (swallow liquids into the lungs), need low-calorie meals due to medical disorders, are allergic to certain foods, or are unable to chew food?

A "typical" lunch could be life-threatening to children with special needs.

Consider Nicki, a seven-year-old girl with head injuries, who cannot chew food and needs it blended to the thickness of pudding. Nicki refuses to eat most vegetables and fruits. Her teacher and parents have noticed that if they mix her food with mashed potatoes, she will eat more. This is crucial because she has lost five pounds in the last year and is now below the fifth percentile when her height-to-weight proportion is graphed on a growth chart.

Liquids also run down Nicki's throat too fast and cause her to choke. The school occupational therapist has recommended that the liquids be thickened using baby food cereal, yogurt or blended fruit, such as applesauce.

How can Nicki's school lunch be modified to make it safer and provide her with the nutrition she needs?

#### School requirements

The Rehabilitation Act of 1973 required recipients of federal funds to make their programs and activities accessible to all individuals with disabilities. Section 504 of the act incorporated new regulations for school meal programs into the Child Nutrition Program Regulations of 1988, commonly known as the breakfast and hot lunch program. These

regulations require schools to modify or make substitutions in meals at no extra charge for students who meet the definition of having a disability and whose disability restricts their diet. A person meets this definition if he or she has a physical or mental impairment which "substantially limits one or more major life activities," has a history of

having such an impairment or is believed to have such an impairment.

Since the Child Nutrition Program Regulations are monitored through the U.S. Department of Agriculture (USDA) rather than the U.S. Department of Education, families and professionals who care for chil-

> dren with special needs are often not aware these regulations exist.

A variety of modifications and substitutions may be necessary to allow a student to consume the meals offered to students without special needs. Some students with gastrostomy tubes may require a liquid formula, while other students may require modifications such as:

- Substitutions of menu items to accommodate such dietary restrictions as allergies, or foods that don't purée well.
- Recipe modification to provide foods that are low or high in certain elements such as fat, sugar, fiber or protein.
- Texture modifications such as thickening liquids, or grinding or chopping foods.
- Other modifications in food characteristics such as temperature, portion size and nutrient composition.



With help from occupational therapist Gloria Frolek Clark, preschooler Derek Harrison practices drinking from a cup.

It is imperative that nutritional value be considered when making any modifications to the meal. For example, if certain foods are prohibited, substituted foods should be similar in nutrient content.

Updated instructions issued in October 1994 by the USDA provide guidance to schools participating in breakfast and hot lunch programs. If a school is not a participant in this federal program, they may still be obligated to make modifications and substitutions based on the Individual with Disabilities Education Act (IDEA). IDEA may require school food authorities to provide meals outside of the regular meal schedule or to provide services that are not usually required by the Child Nutrition Program.

#### Feeding and nutrition goals

Food modifications can be listed on:

- An Individual Education Plan (IEP).
- A Student Health Care Plan attached to the IEP.
- A goals-and-objectives plan related strictly to feeding and nutrition.

Even students who do not qualify for special education services are eligible for special food services as long as they meet the criteria for hav-



254

#### **Special Needs in the Lunchroom**

ing a disability under the Rehabilitation Act of 1973.

In most cases, the school will require a physician's statement regarding the child's disability and related dietary restrictions. The school must determine if this student meets the regulatory criteria of the Rehabilitation Act of 1973, and is only obligated to provide those substitutions and modifications deemed necessary by the physician.

Changing the texture of the mealby such processes as blending, puréeing or chopping—does not require a physician's order, though it is helpful information for the school food service.

#### Inclusion

In addition to meal modifications, the regulations state that food services be provided in the most integrated setting appropriate to the special needs of the student. Unfortunately, students with special feeding needs

often are not integrated into the lunchroom to the maximum extent possible.

#### A team effort

A team approach is critical for a child with feeding and nutrition problems. This approach has made a difference for Nicki.

Nicki has been followed closely by a nutritionist since her parents and occupational therapist became concerned about her weight loss. Her height and weight are being closely monitored by the school nurse and her regular physician. The nutritionist also discussed the need for supplemental vitamins and minerals because of the anticonvulsant medication she takes daily. The educational team has met to discuss the school food modifications that were needed for Nicki. The family, teacher, occupational therapist and nutritionist provided input that was used to develop a plan. The physician had been kept informed of Nicki's needs and difficulties with the school lunch.

As a result of this team effort, specially prepared meals are now available each day for Nicki's lunch. Nicki's teacher keeps in constant contact with the school lunch supervisor regarding the modifications and how they are working for Nicki.

For more information about school food regulations, contact the food and nutrition service staff at your state Department of Education, or your local school district administrator. EP

Occupational therapist Gloria Frolek Clark, OTR/L FAOTA works for the Heartland Area Education Agency in Johnston, Iowa, and is in private practice. She chairs the School System Special Interest Section of the American Occupational Therapy Association. Gloria lives with her husband and three children in Ankeny, Iowa.

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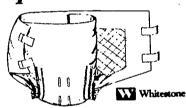
- · residential treatment centers
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## WHAT'S HAPPENING



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three episodes—
"Ways to Move,"

"Ready to Live" and "Redesigning the Human Machine"— explore dramatic advances in technology, medicine and attitudes that are changing the lives of people with disabilities. Ed Roberts, disabilities activist and founder of the Center for Independent Living; Marilyn Hamilton, co-founder of the Quickie wheelchair company and Ed Tessier, a former congressional candidate from California who is quadriplegic, are some of the remarkable people featured.

PEOPLE IN MOTION premieres March 31 at 9 p.m. on PBS (check local listings). A free viewer's guide is available. Write to PEOPLE IN MOTION, P.O. Box 245, Little Falls, NJ 07424-0245.

Twelve-year-old Carl Burnett of Cape
Elizabeth, Maine enjoys "mono-skiing" at
the United Airlines Ski Spectacular, held in
December in Breckenridge, Colorado. The
Spectacular, sponsored by National
Handicapped Sports (NHS), attracted
skiers with disabilities from all over the country. The week-long
event included ski instruction, racing clinics, elite training

#### **Calling Young Playwrights**

The Very Special Arts 1995 Young Playwrights Program has issued a call for scripts written by 12- to 18-year-old playwrights. Scripts must deal with some aspect of disability and must be postmarked by April 14, 1995. The winner of the competition will travel to Washington, DC to see his or her play produced at the John F. Kennedy Center for the Performing Arts.

camps and a giant slalom competition. (Photo: Bruce Barthel)

Very Special Arts is an international organization providing programs in creative writing, dance, drama, music and the visual arts for people with disabilities, especially children and youth. For more information about Very Special Arts, or for details about the 1995 Young Playwrights Program, contact Very Special Arts, The John F. Kennedy Center for the Performing Arts, Education Office, Washington, DC 20566, (202) 628-2800 (voice), (202) 737-0645 (TTY).

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Circle #59



ich

## ASK THE DOCTOR

by David Hirsch, M.D.

## **Infantile Spasms**

At about five months of age, our son developed a type of seizure disorder called infantile spasms. Prior to this time his development was normal. He has brief myoclonic spasms lasting a few seconds but occurring many times each day. After a bout of these spasms, he is irritable, then he seems to become drowsy. He is now one year old and is delayed in all areas. He has been on a number of different anticonvulsants including Valproic acid, benzodiazepine, and ACTH. Nothing has seemed to work very well for any period of time. Recently, I heard about a fairly new medication called "Sabril" that has helped in the treatment of infantile spasms. Is this medication worth trying? A Infantile spasms, sometimes called West syndrome, is a type of seizure disorder with a clinical pattern that most commonly consists of frequent myoclonic spasms (unpredictable contractions of one or more muscle groups) and a unique electroencephalographic (EEG) pattern called "hypsarrhythmia." As in your son's case, most children with infantile spasms develop this condition in the first year of life. Other terms for infantile spasms that describe some other types of seizures associated with it are "lightening" or "jackknife" convulsions.

Unfortunately, infantile spasms are non-responsive to many of the more conventional anticonvulsant medications. ACTH is a hormone that stimulates the release of cortisone. It has been successful in controlling infantile spasms at least for a while, but it has not been shown conclusively to improve the long-term outcome of this disorder.

Vigabatrin, sometimes called Sabril in Europe, is a newer anticonvulsant that has shown some promise in the treatment of infantile spasms and other complicated seizure disorders This medication is now being studied and may become available in the U.S. within a year. It certainly would be worth trying. Continue to work with your son's pediatrician and pediatric neurologist. More information on this medication and other newer treatments for various forms of epilepsy can be obtained from the Epilepsy Foundation of America (4351 Garden City Dr., Landover, MD 20785-2267; 800/332-1000, voice; 800/332-2070, TIY), the American Epilepsy Society (638 Prospect Ave., Hartford, CT 06105-4298; 203/586-7505, voice) or Epilepsy Canada (1470 Peel St., Ste. 745, Montreal, PQ H3A 1T1, 514/845-7855, voice). **EP** 

In this column,
David Hirsch, M.D.,
a pediatrician and
member of
EXCEPTIONAL PARENTS
Editorial Advisory
Board, answers
questions from readers. Dr. Hirsch is a

partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with appropriate professionals. Dr. Hirsch mentions specific products or medications only to illustrate suggestions; he is not sudorsing any specific products.

Send questions to: Ask the Doctor, Exceptional Parent, 209
Harvard St., Ste. 303, Brookline, MA 02144-5005 (617) 750-8742 (fax).

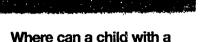


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## **Choosing A Summer Camp**

ummer camp can be a growing experience for a child and a chance for parents to gain some muchneeded respite. Some see summer programs as a way to extend the school year by choosing camps that continue education and therapy goals. Others find the summer a perfect time for their child to get to know other children with and without disabilities.



disability go to camp?

Possible information resources include:

- Parent organizations, especially those affiliated with a national disability organization;
- · Professionals;
- · Social service agencies, rehabili-

tation centers, clinical facilities, or recreational programs;

- · Local Parent Training and Information Centers (see Exceptional Parent's 1995 Resource Guide for a stateby-state listing);
- Local newspapers (Sunday Camp Sky Ranch, Blowing Rock, NC. magazine section) and community parents' newspapers often list camps, camp-referral services and camp fairs;
- · Local religious associations, fraternal associations, community organizations and scouting groups, and
- •Camp guides which may be available at public libraries. Two usefull guides are:

Peterson's Summer Opportunities for Kids and Teenagers, 1995 edition; lists camps and other summer programs for children of all abilities; also available





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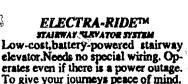


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Circle # 212



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To address Steve's challenges, a comprehensive program, including behavior management and appropriate alternative ways to communicate, was implemented in his classroom, apartment, and outings in the community.

Steve's life is very different now. He's learned to communicate his needs, and his pattern of hitting himself has been reduced to ten "light taps" a day. Now he can concentrate on other skills. Between working his part-time jobs with his job coach, participating in other learning activities, and doing things with his friends, Steve probably won't have time to self-destruct today.

If you know a child who might benefit from an individualized, comprehensive program at Heartspring, call us today. Together we can make a difference.



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#### Circle #3

#### WHAT ABBY DID ON HER SUMMER VACATION

Kids and summer camp is as much an American institution as Mom and Apple Pie. However, parents of children with disabilities discover that finding a camp suited to their child's special needs is not easy. My search for a summer camp for my 13-year-old daughter, Abby, taught me a great deal about parent advocacy.

Diagnosed with spastic triplegia, Abby arrived from Korea at age eight as one of my 10 adopted children. Although mainstreamed in regular classes in middle school, Abby's wheelchair, her

school work and her own demand for achievement created difficulties in making friends. Her chances to make friends were also limited bectuse she traveled alone to school in a special van. Abby desperately needed to leam how to make friends and have fun in a relaxed atmosphere. Camp seemed to be an ideal solution.



Abby Peck attended two one-week sessions at Eagle's Nest summer camp last year: "I did everything the other kids did, and my chair was just no big deal."

To begin my search, I checked with our state special needs coordinator who did a computerized camp search for me. I spoke with people at the regional office of developmental disabilities for referrals. I talked with people on the child study team at school. Our local Cerebral Palsy Association made suggestions. Virtually everyone I spoke to understood the problem and tried to be helpful, but they only referred me to someone else. In the end, I had one solid recommendationa camp for children with disabilities which I felt was unsuited to Abby's needs.

Abby and I changed tactics. We established a new list of requirements: reasonable accessibility, a relatively flat terrain, a swimming program, a low camper-to-counselor ratio and a pro-

gram with an emphasis on individual growth and success. I contacted camps in New Jersey and others within two hours of home.

I was straightforward and open. I talked about "accessibility" as a physical reality and a commitment from the staff. I described Abby, her personal independence in self-care and her physical needs in realistic terms.

Amazingly, our decision was made with ease. The Episcopal Diocese of Newark, of which our own church is a part, has run the Eagle's Nest summer camp for many years. Brad Moore, the diocesan youth director, listened to my well-rehearsed "litany" on accessibility and chuckled. "Sure, she can come," he said. "Just be sure you sign up Alee, too!" The thought that Alee, my 12-year-old sixth grader who also has cerebral palsy, might enjoy camp, too, had never seriously crossed my mind in my one-track quest to provide for Abby.

The staff at Eagle's Nest was well-prepared for Abby. Several counselors-intraining volunteered to help her meet the day-to-day physical challenge of platform tent camping. Some were more successful than others. The administration firmly believed that they could meet Abby's needs and that a camping experience for my daughter could be achieved both safely and realistically.

Abby attended two one-week camp sessions last summer. At the end of the first week, I met her at the bus. Three big, strapping teenagers lifted her off the bus and planted her in my car as she giggled in exhaustion and joy. On the way home, she stretched and sighed in contentment. "You know what, Mom?" she asked. "For the first time ever in my whole life, I feel like a regular, normal kid. I did everything the other kids did, and my chair was just no big deal." I wept quietly for her joy.

--Cynthia V.N. Peck

Cindy Peck is a single adoptive parent of 10 children aged 13-25. She is an English teacher and a partner in Seedlings, a licensed New Jersey adoption agency. She is also the editor/publisher of Roots & Wings, a national adoption magazine. For information and a free sample issue. write to Roots & Wings, P.O. Box 638, Chester, NJ 07930. The Internet e-mail address is Rootswings@aol.com.



#### **Choosing A Summer Camp**

Camp Courageous of Iowa, Monticello, IA.

at bookstores and through Peterson's, Customer Service, P.O. Box 2123, Princeton, NJ 08543-2123, (800) 338-3282 (voice), (609) 452-0966 (fax).

The American Camping
Association (ACA) Guide to
Accredited Camps; lists camps that
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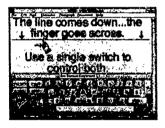
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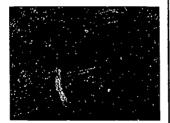
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Circle #80

#### **Choosing A Summer Camp**

includes camps for children with disabilities; offers tips on questions to ask camp directors, what to pack, combating homesickness and financial assistance; also available through ACA, 5000 State Road 67 North, Martinsville, IN 46151-7902, (800) 428-2267 (voice), (317) 342-2065 (fax).

#### "Special" or "Regular"?

A "regular" camp will introduce children to peers without disabilities as well as to peers with disabilities different from their own. A special



Camp Courageous c/i lowa, Monticello, IA.

needs camp is more likely to have the equipment, staff and adaptations needed for all campers to participate in activities. In addition, a special needs camp will provide a child more opportunities to share feelings, thoughts and stories of living with a disability.

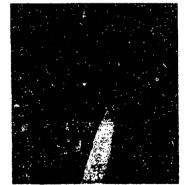
#### **Expectations**

After compiling a list of possible camps, create a list of expectations (parents' and child's) of what the camp will provide. Should it be a fun vacation and/or a time to enhance skills? What do the parents want their child to gain from the experience—friends? increased confidence? a new understanding of the world around them? What are the child's abilities and interests, and how will each of these affect the experience?

When these goals have been determined, a list of questions will help narrow the field of possibilities. Through this list, parents will be able to get a good idea of how the camp

will provide for their child. Directly asking "How will you achieve this?" will help to prepare everyone involved. Some topics that may be covered include:

- Camp objectives;
- Health and medical considerations;
- Staff-to-camper ratios;
- Preparedness of staff to deal with emergencies;
- Physical terrain and accessibility of the camp; and
- References: Speaking with other parents and children



Camp Courageous of Iowa, Monticello, IA.

with disabilities who have attended the camp will give you and your child a more personal view of the camp's potential.

Visiting the camp will let you make sure that the layout and surroundings meet your expectations and needs.

Once all necessary arrangements have been made, summer camp can truly become a time for special memories.

261

-Jennifer M. Koerber

## HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

# A New Insurance Plan for Individuals Considered "High Risk"

My 17-year-old daughter has Down syndrome. I previously worked for a large company and was able to provide her with the best of health care. Now I am self-employed and have no health insurance for her.

My daughter is a healthy teenager. She loves camping, swimming and many other activities that make me nervous. However, I can't restrict her activities just because she lacks adequate health insurance.

Because of her diagnosis, health insurance is extremely expensive. Several insurance companies have said that she is in a high-risk category and prone to having accidents. I can't find an affordable policy.

J.D., Ohio

This issue needs to be dealt with on a national basis. Hopefully, it will be a major goal of Congress. To help persuade Congress of the importance of this issue, it is essential to write to your legislators about your difficulties in obtaining insurance.

In the meantime, The Arc, a national organization on mental retardation, is in the process of establishing a health insurance program the may meet your daughter's needs. "The Arc Group Major Medical Insurance Plan" has been specifically designed to meet the needs of children and adults with Down syndrome and other disabilities, ages 10 to 65.

According to an Arc representative, the policy represents "the only affordable commercial plan that we are aware of in the market today that does not automatically preclude people with mental retardation."

It's important to be aware, however, that this insurance plan is still in the process of development. The information we have is preliminary; specific policy rules may change as final details are developed. In addition, while the program does not automatically exclude applicants with Down syndrome, mental retardation or other disabilities, there is no guarantee of acceptance. Each applicant will be evaluated individually.

#### Two plans

The Arc will offer a "Comprehensive Plan" and an "Economy Plan." Both plans have an individual lifetime limit of \$1 million. Each plan offers three different deductibles, ranging from \$300 to \$1,000 per year.



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Once you have paid the year's deductible, the Comprehensive Plan will pay 80 percent of the next \$5000 of covered expenses. After that, the Comprehensive Plan will pay 100 percent of covered expenses based on "reasonable and customary" charges.

The Economy Plan will pay 70 percent of the next \$10,000 of covered expenses, after the deductible has been met. After that, the Economy Plan will pay 100 percent of covered

expenses based on "reasonable and customary" charges.

#### Coverage

According to the current proposal, both plans will provide coverage for hospitalizations, treatment of mental illness, x-rays, anesthesia, doctors' bills, rental of certain types of medical equipment, ambulance services and laboratory tests. Other medical equipment or services may be covered as well. In addition, there are

specific rules and limits for each of these services, and certain treatments or services are excluded.

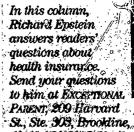
#### **Availability**

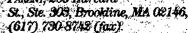
The insurance program will be available to members of The Arc and their families, ages 10 to 65. Unfortunately, The Arc has not yet been able to establish a health insurance policy for children with disabilities under the age of 10, or for adults over 65.

For more information about The Arc Group Major Medical Insurance Plan, write to The Arc's insurance administrator, the Albert H. Wohlers Company, 1440 N. North West Highway, Park Ridge, Illinois 60068-1400, (800) 323-2106 (voice). They will send information as soon as policy booklets are available.

For more information about The Arc itself, or to locate the nearest Arc chapter, call The Arc's national office, (800) 433-5255 (voice) or (817) 277-0553 (TTY). **EP** 

EDITOR'S NOTE: Some states have established state-run health insurance policies for residents who have been unable to obtain private coverage. To find out if your state offers this type of program, contact the Parent Training and Information Center (PTI) in your state. A complete listing of PTI programs can be found in EXCEPTIONAL PARENT'S 1995 RESOURCE GUIDE (January 1995), or the National Parent Network on Disabilities (703/684-6763, V/TTY) can direct you to the nearest PTI.





If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

## EZ-ACCESS

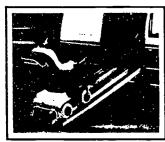
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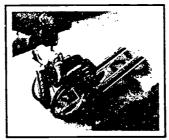




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## Fathers' Voices

# A New Perspective on Development

by Louie Mauro

hen our first child, Alex, was born in 1989, we were armed with an arsenal of child development materials. Books outlining the first years of life, magazines charting the month-by-month progression of the typical infant. We poured over the texts in eager anticipation of each exciting milestone. Each author was careful to explain that every child develops at a different pace, that we should not place too much emphasis on the rather arbitrary averages outlined in the books. Good advice, we thought, as we eagerly charted our son's development to see how he stacked up against the "average" child.

Months passed, and an obvious truth became apparent—our son was exceptional, a prodigy, gifted beyond compare. Although he wasn't yet solving math problems or playing the violin, the way he dropped his rubber ball into Tupperware containers was incredible to behold.

Our pride swelled with each new accomplishment. Alex began crawling at seven months. At 10 months, he was blowing into a kazoo—Mozart probably didn't do that until he was at least a year! At 10 and a half months, Alex was taking his first steps. At 12 months, he was playing hide-and-seek, and at 12 and a half months, he began saying his first words.

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 747-1069 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers regarding their common concerns; develops father support and mentoring programs; and creates curriculum as a means of promoting fathers as significant, nurturing people in their children's and families' lives.



Playing with Daddy: David (left) and Alex enjoy a game of "tickle."

At 13 months, he was struck by a drunk driver. The development books were thrown out. Alex's severe brain injury destroyed most of his former functioning, leaving only unanswered questions. As we dealt with emotions ranging from shock to despair, we somehow tapped an inner source of strength. Believing that "normal" development was still an appropriate goal, we embarked on a plan to bring our child back.

Days turned to weeks, months to years. Therapists manipulated him, doctors prodded him, lab technicians poked at him, but nobody seemed to have any solutions. Alex made some progress, but each subtle improvement was excruciatingly slow and required tremendous effort. Success came in the smallest of gains—the increased movement of his finger or the turn of his head. What once seemed the simplest of tasks—grasping a rubber ball—now appeared hopelessly complex and utterly unattainable.

And yet, transformations were occurring. Not so much in Alex, but in us. Slowly we began to appreciate the little miracles that were never mentioned in the child development books. Like the day when, for the first time since the accident, a tiny corner of Alex's mouth curled up in a barely noticeable smile. Or when we first realized that the "gleam" had returned to his eyes. Those small events would once have been overlooked. But now, with eyes opened by tragedy, we had come to recognize the magnitude of such moments.

In the midst of our transformation came another miracle—the birth of our second son, David. As David grows, our sense of wonder deepens. His developmental



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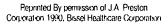
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#### Fathers' Voices

pace is stunning. He initiates movement without our intervention, as if compelled by some innate mechanism. Nor is it necessary to "stimulate" his responsiveness; he interacts as if by magic. Miraculous, "impossible" tasks, like grasping a rubber ball, he accomplishes effortlessly.

Child development books would describe David's progress as "normal" or "average." We know better. We have been offered a glimpse at the complexities attendant with every blink of an eye and every twitch of a finger; with that vision comes a newfound appreciation for the miracle of life. Development—any development—is nothing short of exceptional.

We once viewed the maturation process as something to expect. We now see it as something to revere. We have been blessed with two precious gifts, and for us, each new day is a cause for celebration. **EP** 

Louie Mauro lives with his wife, Donna, and their two sons, Alex, 5, and David, 2, near Sacramento, California. Louie is a Deputy Attorney General with the California Department of Justice, and also serves on the Board of Directors of the Head Trauma Support Project in Sacramento.

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## Kole Models

## **Tony Coelho**

"Epilepsy gave me a mission."

Tony Coelho authored the Americans with Disabilities Act when he was a Democratic congressman from California. Coelho, 52, is now president and CEO of Wertheim Schroder Investment Services, a New York-based asset management firm, and chairman of the President's Committee on Employment of People with Disabilities.

Coelho lives in Alexandria, Virginia with his wife, Phyliss and two teenage daughters, Nicole and Kristi.

was a happy kid, living and working on the family farm in California, good in school, fair at sports and popular with girls. I wanted to be a trial lawyer and later, a priest. I had no idea that my life would not go as planned.

Everything changed when the pickup truck I was riding in flipped over. I got a nasty bump on the head, but you recover fast when you're 15.

I was milking cows when I had my first convulsion—a grand mal seizure. My parents, children of religious Portuguese immigrants, sent me to faith healers, seeking a supernatural explanation for what they couldn't understand. But the convulsions continued.

After high school, I entered Loyola University in Los Angeles, where I was president of the student body. In my senior year, I applied to a Jesuit seminary. They were overjoyed to accept me, an intelligent young leader deeply committed to serving God.

But, the cross I was destined to carry was the stigma of disability, not the crucifix of a priest.

During a routine physical for the seminary, I learned I had epilepsy. Like many with unexplained physical or mental problems, I felt freed.

Now that it was understood that my repeated seizures resulted from a brain injury and could be treated, I thought everything would return to normal.

I realized my naiveté when I broke the news to my father.

"No son of mine has epilepsy!" he shouted. "This one does!" I shouted back.

I then discovered that my parents had known about my epilepsy years earlier, but wouldn't accept it. Centuries-old prejudice held a firm grip on their minds. In medieval times, people who had "fits" were considered possessed by the devil, and for some people, this belief persists.



Richard Marriott, chairman of Host Marriott Corp, talks with Coelho at the President's Committee on Employment of People with Disabilities annual conference, in Atlanta, May, 1994.

#### Relief, but persecution

The diagnosis which had given me such relief was the beginning of the personal and institutional persecution so familiar to people with disabilities.

I was expelled from the seminary. Sorry, they said, but epileptics are not eligible for the priesthood.

When the doctor reported my epilepsy to state authorities, my driver's license was revoked. Soon after, my health insurance was canceled.

Because I wouldn't lie on employment applications, I couldn't get a job. All the offers I'd had since graduation disappeared. Not even the army would take me, though they were drafting others my age for Vietnam.

Nothing about me had changed since taking that physical, but suddenly, I was an "epileptic,"

Booze helped me through the idle days and lonesome nights. I was out of work, out of luck and out of hope, scared to face the future in a world where no one wanted me.

#### Hope from Hope

I had seriously considered suicide until a Jesuit priest provided me with an opportunity to live with the Bob Hope family. Mr. Hope befriended me. "If you find your way blocked," he told me, "find another route to get where you want to be."

He suggested I find a ministry outside the church, perhaps in Congress. So, I began my career in politics.



Coelho at ago 10.





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#### Role Models

What I once considered a curse forced me to face life, shaped me and strengthened me. Above all, it gave me a mission as an advocate for people with disabilities, and God has favored my efforts by granting me so many pulpits from which to speak.

I'm an effective fund raiser for political and charitable causes because I am immune to rejection. Nothing can compare to the rejection I felt when my family refused to acknowledge my epilepsy. No humiliation could be greater than being marked as unworthy of serving God and your country.

Time has not erased the scars. They remain as razor-sharp reminders of that fear, frustration and anger which I want no one else to feel, ever again.

#### Advocacy

In Congress, I wrote and fought for passage of the Americans with Disabilities Act (ADA) to secure the rights of this nation's largest minority. The ADA prohibits discrimination in employment, transportation, telecommunications and public accommodations. It has also sparked a swelling empowerment movement, which is where our future lies.

I served 10 years in the House of Representatives and know how the system works. Advocacy is a personal matter.

No lobbyist can make the case for insurance reform like a mother whose child has been refused coverage because the only available treatment is "experimental."

No lobbyist can express the rage of someone who has recovered from a coma only to find out he cannot get the therapy he needs.

No lobbyist knows the need for personal assistants like the man who once said to me, "What good is the ADA if I can't get out of bed?"

Please, don't ever underestimate the power of your one voice and your one vote. Self-advocacy begins by understanding that rights are never bestowed; they are claimed.

We can't let one law make us complacent, especially now when we are beating at the doors of reform in health care, education and civil rights.

Our fight is not just about tearing down walls and widening doorways. It's a struggle for the soul of America to reaffirm its highest principles of equality and justice. The outcome will be a statement about who we are and who we want to be.

In today's global economy we don't have a worker to waste, yet, in the disability community, unemployment is at 24 percent, nearly four times the national average. Talented, capable people still receive pity and paternalism instead of individual sovereignty. This is bad for us and bad for the country.

Since the November elections, we've been told the people are angry. They want changes. They want results. And they want it now.

So do people with disabilities. We want the barriers removed. We want the chance to work. We want acceptance in our communities. We want our abilities recognized. We want our dignity. And we want it now.

Discrimination hardens you, but it also heightens your awareness of each person's responsibilities to others. We need to inspire those who have lost hope, and become a leadership force for new growth and prosperity. We need to take charge of the issues which affect our families and our nation because we've been waiting in line for a long, long time.

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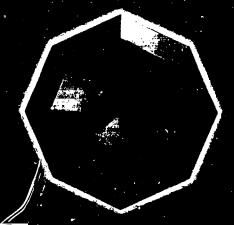


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AMERICA'S DISABILITY CHANNEL

## **Income Tax Tips**

by L. Mark Russell, Arnold E. Grant and Richard W. Fee

amilies that include a member with a disability are often entitled to deductions and credits unavailable to others.

Here is a summary of some items of particular interest.

#### **Exemptions For Dependents**

You can take a deduction of \$2,450 for yourself, and for each person who is your dependent, whether or not the dependent has a disability. This deduction is limited for high-income taxpayers.

A person is considered your dependent if you provide more than half the person's support and the person is related to you. To determine this, compare the amount of support you contributed, with the entire amount of support received from all sources, including the person's own funds and government funds. Support includes money spent to provide food, shelter, clothing, education, health care, health insurance premiums (including premiums for supplementary Medicare coverage), recreation and an allowance. Support is not limited to necessities.

Medical insurance benefits, including Medicare benefits, are not considered part of support. If a dependent receives Social Security benefits and uses them toward his or her own support, the payments are considered as support provided by the dependent. State benefit payments based on need are considered support provided by the state.

If a dependent is a full-time student, scholarships received are not included in total support. This includes the value of education, room and board provided for your dependent. This also applies to payments for room, board and tuition provided for a child attending a special school even if the payments are made by the state.

Unless your child is a student, you cannot claim your child as a dependent if he or she was 19 or older at the end of the year and had a gross income during the year exceeding \$2,450. If your child is a student younger than 24, this gross income test does not apply. If you claim your child as a dependent, your child cannot claim a personal exemption on his or her own return.

#### **Medical Expense Deduction**

A taxpayer is entitled to a tax deduction for medical expenses (which are not reimbursed by health insurance) for the taxpayer and his or her dependents. For these purposes, dependent is

#### **Free Tax Publications**

All IRS publications and forms can be ordered at no charge by calling the IRS toll-free at (800) 829-3676.

Pub. 907, Tax Highlights for Persons with Disabilities, briefly explains tax laws applying to persons with disabilities and directs readers to sources of detailed information, such as: Pub. 502, Medical and Dental Expenses; Pub. 503, Child and Dependent Care Expenses; Pub. 524, Credit for the Elderly or the Disabled; Pub. 525, Taxable and Nontaxable Income; and Pub. 915, Social Security Benefits and Equivalent Ratiroad Retirement Benefits.

defined as above, except that the "gross income test" does not apply. For the purposes of this deduction, the person musc have qualified as a dependent at the time the medical services were provided or when the bill was actually paid.

- Medical expenses are deductible only to the extent they exceed 7.5 percent of "adjusted gross income."
- Medical expenses may be deducted *only* if you itemize your deductions on Schedule A, Form 1040, commonly called the "long form."

A deductible medical expense includes any amount paid for the diagnosis, cure, mitigation, treatment or prevention of disease, or for the purpose of affecting any structure or function of the body and for transportation costs on trips primarily for and essential to medical care. This definition is interpreted broadly; expenses that you may not think are qualifying may be deductible medical expenses.

When families with children who have disabilities deduct large amounts of medical expenses, they may draw special notice from the Internal Revenue Service (IRS). To reduce the IRS's suspicions, describe your child's disability in a letter written by yourself or your child's doctor, and attach it to your tax return.

Also, be sure to store your receipts and canceled checks carefully. Good record keeping is one key to good tax planning.

#### **Tax Credits**

In addition to deductions, a variety of tax credits may be available. Unlike deductions, credits are subtracted directly from taxes due and are therefore more valuable.

- Child and Dependent Care Credit: If you pay someone to care for a dependent so that you and your spouse can work, attend school or look for work, you may be entitled to take the Child and Dependent Care Credit. The limit on work-related care expenses is \$2,400 for one qualifying person and \$4,800 for two or more persons. The credit is computed on Form 2441 if you file Form 1040 or Schedule 2 of Form 1040A.
- Earned Income Oredit: If your adjusted gross income is less than \$23,755 and you had a child with a disability (or a minor child without a disability) living with you for at least six months of the year, you may be entitled to the Earned Income Credit. You may qualify for the credit with an adjusted gross income less than \$25,296 if you had two or more qualifying children living with you.

The amount of the credit is determined from tables published by the IRS. The credit varies depending on income and number of qualifying dependents.

If the credit exceeds the amount of taxes you owe, you can get a refund. Use Schedule EIC of Form 1040 or 1040A to claim the credit. The credit is also available if you use Form 1040EZ.

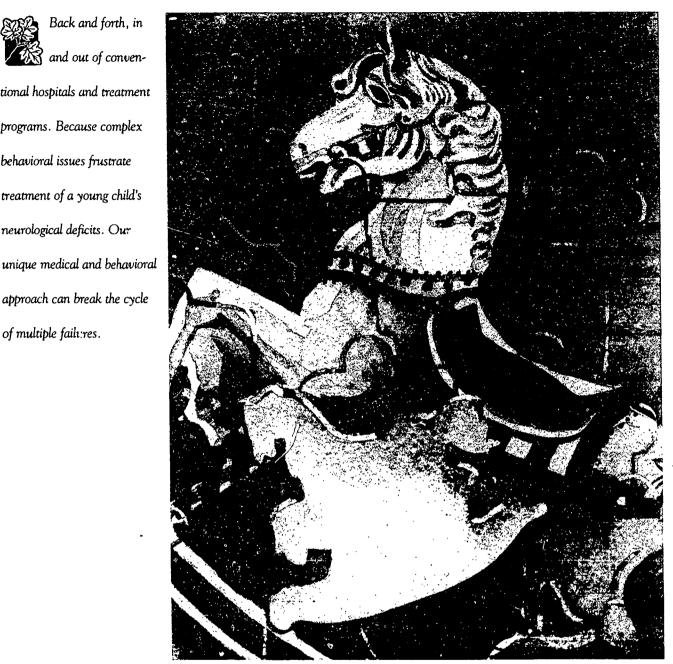
Figuring your taxes can be very complicated. Good luck! EP

This summary is based on PLANNING FOR THE FUTURE, by L. Mark Russell, Arnold E. Grant, Suzanne M. Joseph and Richard W. Fee. Easy to read and understand, this 400-page book is designed as a comprehensive treatment of the life and estate planning process. The book can be ordered from EXCEPTIONAL PARENT LIBRARY (800/535-1910).

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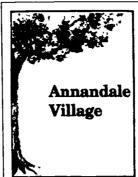
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Circle #132

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Innovative Products, Grand Forks, ND 58201-9983 **Circle # 141** 

#### MINOR-AQUATEC BATHLIFT



switch is available.

This portable, water-powered lift connects to existing plumbing to provide assistance in bathtubs and whirlpools for children with special positioning needs. The unit is operated with a hand control and has numer-

ous accessories and covermat colors. A reclining feature is also available.

Clarke Healthcare Products, Oakdale, PA 15071-9223 Circle # 142

#### **BETTA BABY BOTTLE**

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turer, this bottle has been well-received by parents of children with cleft palates and stomach disorders.

Betta Medical, Sandy, UT 84070

Circle # 143

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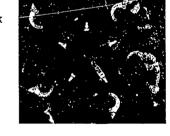
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Floating Swimwear, Wichita, KS 67277

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#### **COOLERS**

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Oticon, Somerset, NJ 08875

Circle # 143

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19.000 products for persons of all ages who have a physical, sensory or cognitive disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers in each listing are to be used on Exceptional Parent's "Free Product & Information Card." Readers can circle a number on this issue's card (page 63) to get more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).



The Newsletter of the National Center for Youth with Disabilities

#### Transition Clinic Opens:

## Project Launch Welcomes Teens and Families

Two adolescents brought their families to the first transition clinic for youth with chronic illness and disability held at Shriners Hospital in Minneapolis, Minnesota, on February 6. They spent the day talking vith professionals and asking many questions.

One :een had concrete goals but needed a plan: What further education do I need? Can I continue my same health insurance if I go out-ofstate to school? Will my health influence my choice of careers? Can the Department of Rehabilitation Services help finance my education? How will I get a personal care attendant?

The other had more personal concerns. How do I find the assistance I

... many young people with chronic illnesses are not receiving special education services....

need to live alone? What if I want to get married? Will the medications I take interfere with birth control?

Both wanted to know how to find a physician. "I've seen my pediatrician since I was a baby. Sometimes I think it would just be easier to stay with him."

These are some of the issues all youth with disabilities face as they move into adulthood, yet few programs exist that provide guidance for youth with disabilities in planning for all their health-related concerns, not just their medical conditions. That's why the University of Minnesota's Adolescent Health Program and the National Center for Youth with Disabilities have joined with the Minnesota Department of Health, Minnesota Children with Special Health Needs; Shriners Hospital, Twin Cities Unit: and the PACER

Center to start this Transition Clinic.

While transition planning occurs in the educational and vocational systems, health issues are not ususally considered. This clinic will be a resource to the other transition services and will work in conjunction with schools and other resources to develop comprehensive approaches.

The truth is that many young people with chronic illnesses are not receiving special education services. Often they have no access to transition planning.

Project Launch: The Independent Living Clinic for Adolescents assists young adults and their families to make successful transitions to adulthood by helping them to develop a plan that addresses issues of health, education, work, social relationships, and physical, emotional and sexual health.

> Project Launch Turn to page 70







While a teenager struggling to gain independence is the cause of many interesting (and some not-so-interesting) family dramas, often it is more poignant a challenge when the teenager has a chronic illness or disability. How often do parents expect their 21-year-old to be independent when the truth is their child has none of the necessary skills to be independent? How often does the system thwart teenagers' development of independence by keeping them in pediatric care?

If professionals want to help youth with chronic illness and disabilities achieve independence, they may just have to "re-think" their responsibilities to the adolescents with whom they work. Chronic illness and disabilities often place young people in a dependent role, precisely the opposite of their need to take control over their own lives and become adults. Teens need to learn how to make decisions and how to deal with success and failure. But they can't do it alone. To encourage independence, parents must be able to shift responsibility to the adolescent. The extent to which an adolescent can become independent depends on the degree of disability, the family's psychological support, financial situation, and the teen's motivation. For optimum development, teens with disabilities must have access to the same life opportunities as their peers, and they need to have equal opportunity to participate, succeed, and fail in those activities.

That's really what the articles on these pages are about: Encouraging independence. Building transitions. Every adolescent with a chronic illness or disability should have an "independence" plan. For most teens, planning for the future, dating, having a driver's license, being enrolled in school, and finding a job are critical to independence. Youth with disabilities may not achieve each of these milestones without special, formal attention to developing a plan. We highlight one program that is trying to fill the gap between pediatric care to adult health care. But more important, NCYD is conducting a survey to identify formal transition programs across the country. Please fill in the form on the next page if you know of one.

We also highlight some of the differences between care provided by a pediatrician and care provided by an internist that might be useful to families when considering change. We received so many positive comments when it was originally published in the fa!, 1994, issue of *Connections* (the newsletter of the National Center for Youth with Disabilities), that we decided to offer it to a wider audience. But there are other choices and models of health care. Some families find family practice physicians meet their needs throughout the life cycle and some teens have positive and valuable experiences in school-based and other adolescent health centers.

**PMR** 

Project Launch From page 69

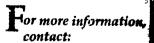
Each teen and family has the opportunity to meet with a variety of professionals. The goal, however, is to start with what the young person identifies as the most pressing needs. Most teens will not need to see every professional; the clinic allows for a variety of consultations.

- Was A nurse or social worker can review general health care issues, discuss insurance options, and consult on issues surrounding social activities and expectations;
- A physician trained in adolescent medicine can help a young person identify medical and physiological issues, including making plans for ongoing care and the implications for healthy sexual development. The physician can answer questions about reproduction, childbearing and sexual vulnerability; make recommendations for contraception, manage menstrual disorders, and assist in the prevention of sexually transmitted
- A psychologist can discuss psychosocial issues surrounding the transition from adolescence to adulthood—gaining independence, learning styles, managing selfcare, identifying adolescent health risks and their impact;

- A vocational counselor can help a teenager evaluate past work experience, explore career interests, train and assess needs, and assist in identifying strategies to meet individual goals;
- A family resource coordinator can help the young person with disabilities and the family link up with community agencies, schools, physicians, and others as necessary.

Some young people will require additional professional assessment. For them, specialists may include nutritionists; genetic counselors; educators; psychiatrists; occupational, physical and speech therapists; and financial or legal counselors.

Project Launch is a demonstration project available at no direct cost to families or the referring professional or agency. This program will be evaluated for consumer satisfaction and perceived usefulness.



Nancy Okinow NCYD Box 721 University of Minnesota 420 Delaware St. S.E. Minneapolis, MN 55455

## **Calling All Transition Programs**

The National Center for Youth with Disabilities NCYD) wants to identify hose transition programs cross the nation that help adolescents with hronic illness and disability move from hediatric to adult-focused health care.

If you participate in, direct, or know of any formal transition program that meets one of the criteria above, complete this form and mail or fax it to:

Peter Scal NCYD Box 721 University of Minnesota 420 Delaware St. SE Minneapolis, MN 55455 Fax: 612-626-2134 What makes a transition program for health care? A formal health care transition program incorporates one or more of the following elements:

Professional and environmental or institutional support for the concept of transition of health care;

Recognition and encouragement that the responsibility for decision-making and consent needs to move from the parents to the adolescent;

Professional sensitivity to the psychosocial issues of disability and chronic illness;

Primary and preventive care in addition to care for the chronic condition;

Commitment to health education.

The number of adolescents who survive into adulthood because of better medical practices is increasing all the time. Unfortunately, there is little basic information about the health transition services that are necessary to meet their needs. Descriptions and program evaluations of various models—including family practice models—are scarce.

NCYD is conducting a survey to identify transition programs; these will then be the focus of a more detailed study. A report describing the characteristics of various program models will be compiled and disseminated to a wide audience. Such

information will encourage and facilitate the development of new programs.

Inquiries about
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University of Minnesota Box 721 420 Delaware St. S.E. Minneapolis, MN 55455 1-800-333-6293/ 612-626-2825

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Adolescents with Chronic Illness and Disabilities:

## Managing Health Care Between Cultures

Moving teens from pediatric to adult health care can often be complicated. There can be many choices. Some teens receive care from family practice physicians. Some use school-based health clinics that provide appropriate referrals.

For most, the dilemma arises in moving from their pediatrician to an internist for primary care. And they can provide very different types of care.

"Training in either discipline socializes young pediatricians and internists to the unique comportment of their chosen fields," David Rosen, M.D., M.P.H., explains. Rosen has one foot in adult medicine and another in pediatrics. While aware of the limitations of stereotypes, Dr. Rosen describes the various differences between the disciplines:

The National Center for Youth with Disabilities is a program of the Society for Adolescent Medicine and the Adolescent Health Programs at the University of Minnesota. Publication of Youth Connections is supported, in part, by project MCJ-275045 from the Maternal & Child Health program (Title V, Social Security Act), Health Resources & Services Administration. Department of Health & Human Services.

The Center's mission is to improve the health and social functioning of youth with disabilities through providing technical assisstance and consultation, dissseminating information, and increasing the coordination of services between the health care system and others. Center activities are directed at enabling youth to become full participants in their communities.

#### Internist

- The internist is a clinical problem solver determined to come to terms with the presenting problem.
- The internist sees patients when growth and development are complete. They are less likely to expect continued improvement and development; rather, they look to remediation to ward off inevitable deterioration in health.
- The internist sees patients who are ill, often with conditions that deteriorate over time, and frequently with illnesses associated with adult lifestyle choices that include tobacco, alcohol and other drug use, poor diet, lack of exercise, etc.
- The internist sees patients who are expected to function autonomously.
- The internist communicates directly with the patient.

#### Pediatrician

- The pedatrician, while also a problem solver, balances the practical needs of patient and diagnostic curiosity.
- The pediatrician facilitates a child's growth and development over time and observes their patients becoming more capable.
- The pediatrician sees patients who are healthy most of the time and few are ever perceived as having direct "responsibilty" for their condition or ill-health.
- The pediatrician views families as critical to the well-being of children and adolescents.
- The pediatrician communicates with parents and other family members, often before communicating with the patient.



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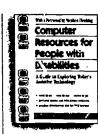
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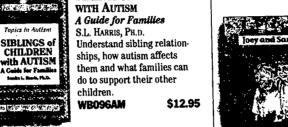


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## CHILDREN'S PAGE

## My Wheelchair

by Emily Brush

hen I first heard that I was getting a power wheelchair, I wasn't sure that I would like it because I wanted to walk—just like anyone else. But then I found out it was

going to be my favorite color—yellow—and I decided I liked the idea!

I got my power wheelchair when I was five years old. I have been driving now for three years. I like my power chair because I can go wherever I want. I like driving my chair at school, at home, at the mall, at the playground and at the Price Club where they have special shopping carts that attach to my wheelchair so I can help my mom shop.

In school, some of the other kids ask me why I can't walk. I tell them I have something called a handicap. Maybe I'll be able to walk when I get a little older, but for now, I get around just fine in my chair. **EP** 

Emily, 8, is in the second grade at the Edith M. Griebling Elementary School in Howell Township, New Jersey. She lives with her mom and dad.

Diane and
Gary, and
Smokey, her
cat. Emily
has athetoid
cerebral
palsy.



Emily, 8, enjoyed Thanksgiving dinner last year with her good friends, Michelle (left) and Angela (right) Tuchol.



When Emily was six and a half, she spent Easter Sunday in New York City with her family.



Emily, 7, at her Brownie Inception. With her is her dad, Gary.

Mom's Turn: Power mobility has done much to enhance the quality of Emily's life. It has been a boon to her self-esteem and a confidence-builder. It has given her independence and freedom where she had none. When in the "driver's seat," she is the one in control and becomes the decision-maker. She alone can decide where to go, how fast and in what direction. Emily used to be very passive on our trips to the mall, content to be pushed wherever others wanted to go. Now she takes a more active role and helps set the pace. We welcome Emily's new-found assertiveness and the negotiating that now accompanies

-Diane Brush

our outings!



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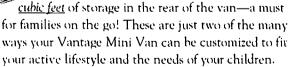
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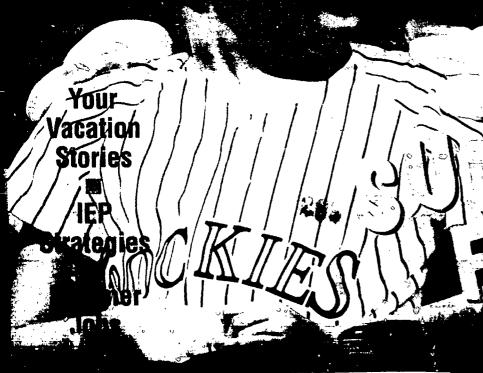
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# PARENTING The Magazine for Pamilies and Professionals

APRIL 1995 VOL. 25, ISSUE 4



PAGE 34

# YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

Since 1971

Cover: Ryan In't Veld of Belle Fourch: South Dakota with Mickey Mouse during his vacation to Walt Disney World. Ryan, who has Duchenne muscular dystrophy, spent six days visiting many attractions in the Orlando area. The trip was sponsored by Give Kids the World, a nonprofit organization that gives children with life-threatening conditions and their families all-expense-paid vacations to central Florida and its famous attractions.

Ryan, 11, shared his visit to Disney with brother Andrew, 13, sister Elise, 8, and parents Arlen and Sue. Ryan is a fifth-grader at the Belle Fourche Middle School.

For more information on Give Kids the World, contact them at 210 S. Bass Rd., Kissimmee, FL 34746, (407) 396-1114 (voice), (407) 396-1207 (fax). Photo: Wallace Sears, Walt Disney World.

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#### SUMMER FUN

And We Thought Planning Was the Key by Nancy Sturm	29
Despute some problems write camping, one family continues to vacation	
Readers Talk About: VACATIONS	32
Readers Talk About: VACATIONS  CAREFUL PLANNING AND A POSITIVE ATTITUDE by Mindy Williams.	32
DOE NORTH by Paulette Gaia	34
A DISNEY BIRTHDAY by Alice Mudge	36
FAMILY CAMPING by Theresa and James Moran	38
SURF'S UP! by Helen and Joe Markee	39
SHARING THE WORLD WITH OUR CHILDREN by Georgia and Gary Freedman-Harvey	40
Travel Resources	42
A guide to organizations, publications, hotels, van rentals and theme parks.	
The Ultimate Playground: Amusement Parks by Donna G. Albrecht Tips for enjoying theme parks.	46
Features	
Help Wanted	54
Summer and part-time jobs can provide valuable experience.	T
IEP Strategies by Barbara Ebenstein	62
Getting what your child needs from IEP meetings.	VL
Departments Editor's Desk	•
Letters	2
Search & Respond	4
Role Models: Tom Suturian	10
Role Models: Tom Sullivan	<b>.22</b>
Media: When Young Children Are Injured	27
Familiar Faces.	48
Fathers' Voices: Hey, Mister! Is She Retarded? by Steve Volkert	53
Research: Preventing School Failure by Louisa Moats	60
Instructional needs for students with learning disabilities.	
Ask the Doctor: Hypotonia; Gastrointestinal Problems	64
What's Happening	65
Directory of Advertisers	AA
New Products	60
Health Insurance Troubleshooter: Cutting Costs in Medicaid and Medicare	7n
Informational Forum: Networking	70
Exceptional Parent Library	 CO
Children's Page: I Love My Brother by Ivan G. Smith	
To the state of the control of the c	84



290

# EDITOR'S DESK

s we developed material on summer planning, we also decided to include information about jobs. Summer is the time when many young people first think about getting a job—and this important summer activity also requires planning. Unfortunately, many young people with disabilities miss out on the typical adolescent

STANLEY D. KLEIN, PH.D.

experience of summer and part-time jobs. While parents, professionals and people with disabilities have worked very hard to create educational and recreational opportunities in their communities, we don't know of many opportunities for young people with disabilities to learn the essential job skills so many of us learned on our first jobs—getting to work on time, meeting deadlines, getting along with co-workers and doing what we are told—even if we don't like it. These experiences often help us to discover new interests and abilities. In fact, the summer job I held after my first year at college in 1954—working at a camp for children with disabilities—changed my career plans.

We hope readers will encourage employers to begin offering job opportunities to young people with disabilities. One of our summer editorial interns in 1994 was a high school student with special health care needs.

#### All kinds of fun

Thanks to the many readers who responded to our request to share stories about memorable family vacations. It has been exciting to read these wonderful stories of how parents and children are finding ways to enjoy a variety of different types of vacations. Though not every vacation described will be the right fit for every family, we know these stories will inspire readers.

We are especially grateful for the kind assistance of the wonderful people at Walt Disney World for helping us to create a great cover. Thanks to photographer Wallace Sears for his great photo of Ryan In't Veld and Mickey Mouse.

**Changes in Washington** 

Networking describes key changes in Congress that have taken place since the November elections. We congratulate the new congressional committee chairpersons and staff members. We look forward to helping them get their messages to our readers.

Some of the concerns that advocates have raised have been addressed. At the same time, we encourage readers to share the suggestions of Richard Epstein, our Health Insurance Troubleshooter columnist, with their elected representatives. Parents, people with disabilities, advocates and political leaders can be proud of the wonderful improvements in attitudes about people with disabilities as well as the ever-increasing opportunities and expectations for participation in community life that have come about because of important legislation. However, there are many areas that still require change or need to be improved. Our leaders welcome and need our input.

**Education Program Awards** 

It's time again to invite nominations for this year's Exceptional Parent Annual Educational Program Awards. Programs will be judged on criteria such as attention to the needs of the whole child-academic, social and recreational; teacher support and parental and community participation.

The awards—known in the past as the Mainstreaming Awards and Inclusion Awards—recognize good educational choices for parents and children. Although we are advocates of inclusion when it includes the necessary support services, we realize that there are successful programs that are not inclusive.

Entries, of 500 words or less, should explain the success of the program. Also, please send photographs. Send nominations to Exceptional Parent Annual Educational Program Awards, 209 Harvard St., Ste. 303, Brookline, MA 02146. Deadline for entries is July 1, 1995.



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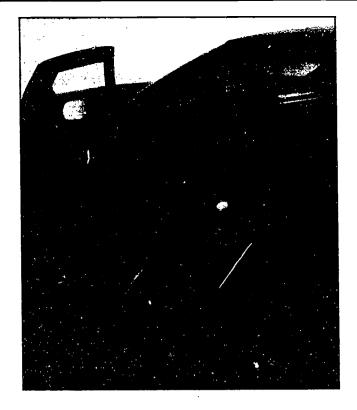
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# LETTERS

#### Struggling for Inclusion

After reading the letter "Inclusion Article Misleading" (November 1994), I felt a reply was needed. It is obvious that J.R. in New Jersey and her husband are having a difficult time effectively "including" their son. It is always a struggle—no matter the family, the child, the disability or the community.

In responding to the article "Making Inclusion Work" (September 1994), J.R. characterizes the services Angela Hart receives as "amenities." They are not. They are Angela's civil rights as dictated by the U.S. Constitution, the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA).

In her letter, J.R. describes her struggle to "convince" her daughter's team to meet more often. The article about Angela's inclusion describes a program, not the path to that program. This program is not exceptional; there are programs like it all over the country—some better, some not as far along. However, rarely do programs like this happen through "convincing." I know.

When we lived in Connecticut, we struggled long and mightily. We often got the services our child was entitled to only after our lawyer attended meetings that we legally called on our own. Many, if not most school districts, will provide services only when they have "a gun to their heads"—very sad, but very true. (We have since moved to a more welconing school district in Kansas.)

J.R.—Your child will only participate and flourish in an inclusion program if you want this for him and are relentless. If the struggle is too challenging in your own community, you may find it feasible to explore other communities. If not, circle the wagons and get support from local groups and other parents, including the parents of your child's peers who do not have disabilities. Be prepared to make friends and enemies and enrich your lives and the lives of those with whom you come in contact.

continued on page 6

#### From Grief to New Dreams

I was very impressed by "Grieving a Dream" by Susan Blanchard (October 1994). It brought me back to my own grieving process more than 35 years ago...

I married late in life and my first child was born with Down Syndrome. Receiving "the news" from my doctor when Lisa was three months old was a traumatic experience. I still recall my husband's response to my distress. He asked me to answer this question honestly: "Is Lisa any less precious today than she was before the doctor gave you the news?"

Because I have always been extremely honest about my feelings, and maybe because I had always dreamed of a daughter who would go to college, my answer

was "yes." All my dreams for Lisa had been shattered.

My grieving manifested itself in horrendous emotions— I wished I were dead; I wished something would happen to both Lisa and me. I was very jealous of my three girlfriends, who also

had married late in life, but had given birth to "normal" babies. I still recall how incredulous my husband was when I confessed that when I gave Lisa a bath, I was tempted to fill the bassinet up to the top.

These thoughts and feelings aroused incredible guilt, and I was sure I would be punished for them. I thought there was something radically wrong with me until I read Wolf Wolfsenberger's research on the initial reactions of parents to the news that their child has a disability. Wolfsenberger mentioned emotions like alarm, ambivalence, anguish, avoidance, bitterness, confusion,

Lisa (right) and brother Paul show off their Easter paracle outfits in 1961.

clenial, depression, despair, disbelief, envy, guilt, impulse to destroy, overidentification, remorse and shame—I could identify with them all.

As Susan Blanchard stated, the grieving process is a continuous one. Even the best adjusted parent will face many occasions that re-evoke intense feelings of grief. Feelings never completely disappear; they remain part of our emotional life forever. It is important that we acknowledge that these feelings are a normal

response to an abnormal situation.

I believe it was healthy for me to admit to these feelings and to talk about them. Shedding my guilt about these feelings freed ma to help Lisa become the terrific human being she is. I became able to have

dreams and visions of the things Lisa would be able to do. I worked hard at making her as independent as possible, and I "let go" at a very early age.

Thirty-five years ago, most parents of children with disabilities had nightmares about the future, not the dreams and visions of today's young parents. I urge all of you young parents to move beyond grieving, and start dreaming of the many things your children can do. With more integration, higher expectations and more risk-taking, our sons and daughters will reach new heights.

Betty Pendler New York, New York



Lisa and Betty Pendler celebrate Betty's birthday in 1988.





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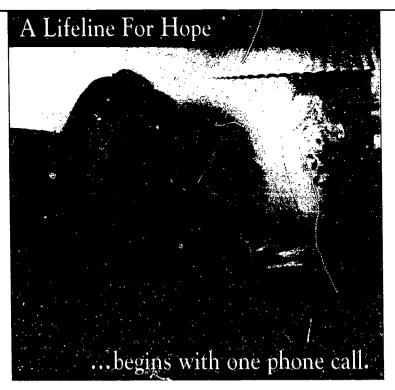
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#### LETTERS

continued from page 4

Inclusion of J.R.'s child will benefit every child, teacher, parent, civic leader and administrator who rubs up against it. It is up to J.R. and her husband to carry on the struggle. J.R., we are all here to help; your struggle is ours. Include us in it and include those close to you, too. You cannot do it alone.

H.R., Kansas

#### **Responding to Albert Shanker**

As a parent-advocate and the parent of an "included" child attending school in New York state, I was surprised to see Albert Shanker's article ("Inclusion and Ideology," September 1994) reproduced in your magazine.

While I understand that not all parents want or are ready for inclusion, I also believe that special education should not be "segregated." Separate schools and classes create concentrations of similar disabilities. In such situations, where are our children's role models? How does a child with a speech impairment learn to speak if no other child in the class can speak?

For many years, speech therapists told me that my child "did not communicate with her peers" when placed in a therapy room with two other children with disabilities. However, when mainstreamed at lunch, she had no difficulty communicating successfully. The problem was that she had nothing to say to the two children in the therapy room.

My daughter's inclusion has been a success because it has been done properly. I thank my school district and all the staff and parents who have worked very hard to make it so. We were pioneers who led the way for others.

The inclusion movement does not continued on page 8

#### Tell us about...

## ...experiences with genetic counseling.

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.

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continued from page 6

seek to remove the choice from parents but to ensure that all parents are truly given the opportunity to examine a full array of options. I agree with Mr. Shanker that sweeping policies that determine what is "good for all" should be viewed with skepticism. But who will play God and determine which child is to be given a chance?

C.F., New York

#### **Best of Both Worlds**

I wanted to take this opportunity to let others know what a wonderful magazine *Exceptional Parent* is. I have received only a few issues, but I truly enjoyed them. They have been informative, encouraging and supportive.

Exceptional Parent is the perfect title because having a child with a disability makes our lives truly exceptional. We have a three-year-old daughter with Tay-Sachs disease, a progressive, neurological deterioration which leads to death in early childhood. Naturally, we were devastated when we found out, but our daughter seems happy, feels loved and gives so much love back to us.

We also have eight-month-old twin daughters who do not have Tay-Sachs. We feel really blessed to have the best of both worlds. Our lives feel so full and rich with all of our experiences. We have really learned to appreciate all of our family and friends.

D.R. & L.R., Ohio

#### Thanks from a Grandparent

I'm writing to you about my grandson, Andy, who has Down syndrome. Before Andy was born in 1991, I had never even heard of Down syndrome. We knew there was something wrong with Andy, but we didn't know what. It took the doctors four days to find out.

Andy started attending a school for children with disabilities by the time he was 18 months old. This is where I found out about *Exceptional Parent*.

One of Andy's teachers gave me a copy, and now I subscribe. I read it and learn something new all the time.

I would like to thank you for the great job you are doing for kids with disabilities. The information you provide is invaluable to people like me.

W.G., Tennessee

#### Problems with Search and Respond

I am really pleased that you will begin printing names in the *Letters* section for those who wish to have this information printed. However, I am disappointed that you will not be printing names and addresses in *Search*.

Although I understand your reasons, my disappointment has to do with my experiences responding to Search letters. I have responded to a handful of Search letters over the past two to three years, but have never once received a reply, nor have I seen my responses printed. Okay, maybe my responses were not the best choices to be printed in the magazine, but I don't want to believe that the parents who received my response letters chose not reply to me personally. That leaves me with this question: "Were my letters actually received and forwarded by Exceptional Parent magazine?"

It's frustrating to make efforts to connect with others, but not even know if my letters made it through. It has soured me somewhat to the idea of responding to any more letters. I haven't yet tried to do a *Search* myself, but perhaps it is time to try. You can bet I will reply to every response I receive.

Would you at least consider mailing a postcard to responding parties to acknowledge receipt or to indicate that our letters have been forwarded?

Rosanne B. Thorn Lynn, Massachusetts

EDITOR'S NOTE: Thank you for your suggestion. We have started acknowledging all SEARCH and RESPOND letters received in our editorial offices. All responses to SEARCH letters are forwarded; due to space limitations, only a small fraction can be published in RESPOND. Space limitations also prevent us from printing all the SEARCH letters we receive.



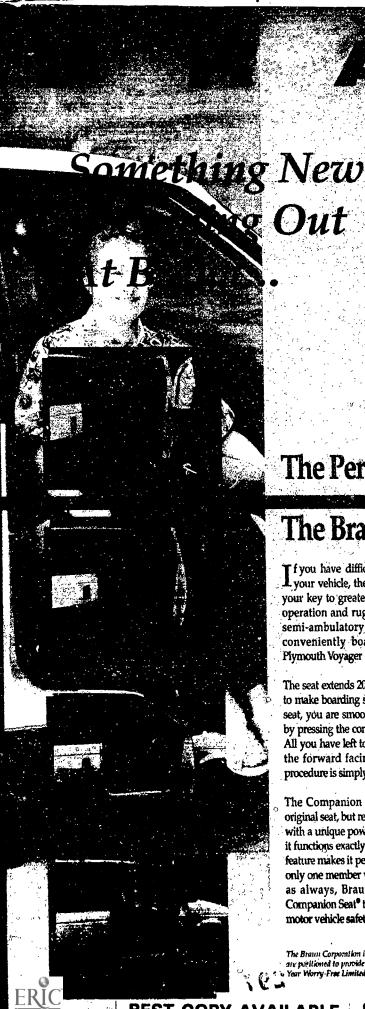
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# SEARCH

#### One Twin with Down Syndrome

I have fraternal twins—a boy and a girl—Cameron and Catie. The twins have a close bond with each other. Cameron has Down syndrome, and is very high-functioning. We try to treat him like our other children, with maybe a little closer attention to helping him develop language and appropriate manners.

My main concern has to do with educational planning. I want to do what's best for each of them and both of them. Catie presently goes to an early child-hood program with Cameron, and it has worked out great. But how long can I keep them together without holding her back? Catie wants to go to HeadStart with Cameron, but she's ready for kindergarten.

I would like to hear the first-hand experiences of other parents with a similar situation.

N.M., Minnesota

#### **Swinging Objects**

My son is 10 years old and has Down syndrome. He takes Synthroid for

hypothyroidism, but has no other physical impairments. However, since he was a baby, he has had a tendency to focus on objects that he can hold and swing around. This behavior is almost always accompanied by talking to himself and, sometimes, by spinning in circles.

As he's gotten older, this need to swing objects and talk to himself has become stronger. It has become a problem at school. He seems to "zone out" at these times and becomes angry when we interrupt him. We've come to our wit's end in trying to understand and lessen the frequency of this behavior, if not eliminate it altogether. Any suggestions would be greatly appreciated.

C.T., New York

#### **Sanitary Pads**

My 10-year-old daughter is lovely, funny and, quite simply, beautiful! She has cerebral palsy—athetoid type—and is a quadriplegic. She has total bowel and bladder control. She can knee-walk and crawl and has lets of movement, both controlled and involuntary.

My daughter will soon be dealing

with puberty and the beginning of her menses. I am searching for a sanitary pad that will actually work and stay in place. Her body build is slim and petite. Physical appearance and fashion are very important to my daughter, so it is very important that we find a pad that won't be visible and won't leak. I'll be very grateful for any suggestions.

M.K., Arizona

#### Stressful Car Rides

My 26-month-old son, Austin, does not have a specific diagnosis, but has been labeled "centrally hypotonic." Austin becomes very upset when riding in a car in a car seat. Because he is still basically non-verbal, he is unable to explain what is bothering him.

Austin has had—and still has—some sensory processing problems including a lack of response to pain. He is often unaware of food in his mouth and will hold it there for prolonged periods. Austin loves roughhousing with his siblings and enjoys movement-oriented activities. He walked at 23 months.

continued on page 12



- ➤ To reach out to parents of children with disabilities and special health care needs.
- To empower mothers and fathers by providing practical information and emotional support.

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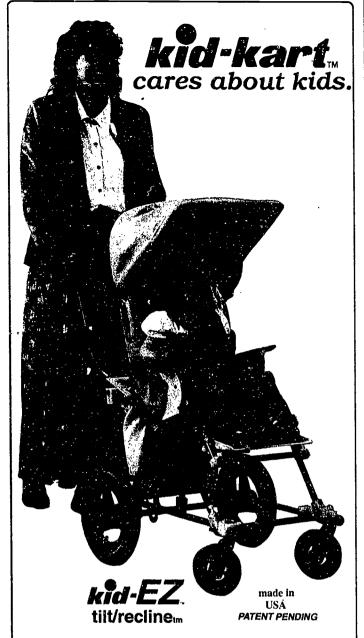
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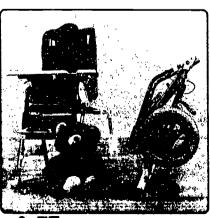


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Base

#### SEARCH

continued from page 10

We have tried different car seats and different seats within the car. His occupational therapist has checked his positioning in the seat and feels he is physically comfortable. However, he becomes upset immediately when we put him in the car—crying, screaming and holding his breath until he passes out, sometimes four or more times during a 15-minute car ride.

While riding in the car, we try to calm him—first with distractions, and then with a bottle or pacifier. We are looking for any ideas or activities to help make car rides less upsetting for Austin and less stressful for us and for his siblings.

C.R., Ohio

EDITOR'S NOTE: Editorial Advisory Board member and Ask the Doctor columnist David Hirsch, M.D. responds: "It sounds like Austin has global delays. I would also be concerned about his vision—especially the way he perceives moving objects—as well as his hearing and balance. I would also want to know if he has any problems with sweating or regulation of body temperature. Because of Austin's lack of response to pain, I would suggest he be evaluated for the possibility of a peripheral sensory neuropathy."

**Desperately Seeking Van** 

My 17-year-old daughter has cerebral palsy and uses a wheelchair. She will never walk and I am finding it increasingly difficult to lift her in and out of our car.

We desperately need a wheelchair van—one that will not break down in the middle of nowhere since we live in a rural area. Many agencies have offered to help us adapt a van to accommodate Wendy, but we must find a van first. We cannot afford a good used van, and we do not have enough money to make monthly payments on a new one. Does anyone know of an agency that would help us obtain a van that can be adapted or one that is already adapted?

A.M., Arkansas

Entron's Note: Editorial Advisory Board member and Ask the Doctor columnist David Hirsch, M.D. suggests that C.T.'s son be evaluated by a developmental behavioral specialist for the possibility that he has a pervasive developmental disorder (autistic-like characteristics) in addition to Down syndrome. Dr. Hirsch also recommends that the child's vision and hearing be carefully evaluated.

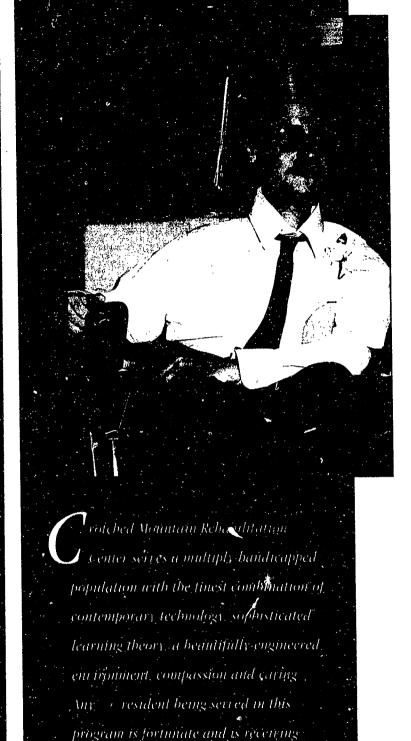
#### **Maternal Disomy of Chromosome 14**

My youngest daughter, Elyse, 4, has been diagnosed with a maternal unipagental disomy of chromosome 14. This means she received two strands of chromosome 14 from me, rather than receiving one from me and one from her father.

Doctors tell us she is one of a few children in the world with this disorder. We are looking for information about this condition and contact with other families.

J.T., New South Wales, Australia

continued on page 14



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Circle # 73

continued from page 12

#### Omphalocele

My six-month-old daughter was born with a large omphalocele; her entire liver was outside of her body. I am looking for information about the development of children born with this condition. I'd like to know about things like growth patterns, motor skills, weight gains/losses and feeding difficulties.

L.S., Connecticut

#### **Dandy-Walker Syndrome**

Our five-year-old son, Michael, was diagnosed with a variant of Dandy-Walker syndrome at six months of age. My husband and I carry recessive genes for this disorder. Michael's symptoms include low muscle tone, an extra finger, a large head, a malformed cerebellum and a lack of balance and coordination. At the age of four and a half, he is the size of a two-year-old.

Michael is non-verbal but is very receptive and expressive. He uses some sign language and picture books

to communicate. He does not stand without support, but he can crawl and walk with a walker.

We would like to hear from parents and professionals who have experience with Dandy-Walker syndrome. We would also like to hear from families who carry a recessive gene for this disorder. We want to have another child, but know there is a risk involved.

C.K., Colorado

EDITOR'S NOTE: The Dandy Walker S-mdrome Network (5030 142nd Path West, Apple Valley, MN 55124; 612/423-4008, voice) can provide information about the syndrome. They can also help you make contact with other families in the U.S., Canada and England.

#### Autism and Spina Bifida

I am the mother of a four-year-old son who was born with spina bifida and also has autism. We have not heard of another child with the same challenges. We would like to hear from anyone who has a child like ours.

M.K., Iowa

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax: Search or Respond Exceptional Parent 209 Harvard Street, Suite 303 Brookline, MA 02146-5005 Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in Exceptional Paper's 1935 Resource Guide (January 1995).



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# RESPOND

### Deafness and Motor Impairments

T.K. (December 1994) is the parent of five-year-old Eleanore, who was born with hypotonia and cerebral palsy affecting the right side of her body. Eleanore has always been exceptionally visually alert and socially aware. Though making steady progress in motor skills, she did not develop language. Last summer, she was diagnosed as profoundly deaf. T.K. asked for positive stories about children with motor impairments and deafness, especially those whose deafness was diagnosed late.

My 14-year-old daughter, Justine, has athetoid cerebral palsy and is also profoundly deaf. I learned Justine was deaf when she was four months old, however, it took me at least five years to become fluent in sign language.

Justine is mainstreamed in a public high school. She uses American Sign Language and attends school with an educational interpreter/aide. She plans to attend college or technical school. Justine recently got a laptop computer that also functions as an augmentative communication device so she can communicate more easily with people who do not understand sign language. Justine's expressive signs are hard to understand because her arms and trunk are most affected by her cerebral palsy. This makes the augmentative communication system essential for her.

My daughter is beautiful, bright and very outgoing. She has a new boyfriend, who is hearing and uses a wheelchair; they communicate with the aid of the computer. Justine's future looks bright, although 14 years ago, I did not think so.

As for your daughter, Eleanore—she needs language, and fast! A late diagnosis of deafness is not uncommon, but that makes the challenge for you more difficult. My advice is to learn as much sign language as you can, so you can give Eleanore a language base.

The best way to learn sign language is to be with people who are deaf. If Montana has a state school for the deaf, they probably offer sign language

classes. Another idea is to bring deaf people to you. We have personal care workers in our home; in the past, we have hired deaf women.

You will need to access the deaf community to learn their language, however, Eleanore may never be accepted as a full-fledged member of that community. Many deaf people identify themselves as members of a cultural and linguistic minority group. Most do not think of deafness as a disability.

Justine attended the Wisconsin School for the Deaf for many years, but she is accepted better now as a mainstreamed student in a "hearing school."

Since Eleanore has coordination problems and limited use of her right arm, you might have her evaluated for augmentative communication. At the same time, you should encourage Eleanore to sign for herself. Many signs require fine motor coordination, however, you and your family will be able to understand her signs. Justine's signs aren't perfect, but I can understand them, and others who know her well can, too.

I can tell by your letter that you have positive goals for Eleanore, and so you should. Nothing in my life has been as rewarding as raising Justine. I couldn't be prouder of her accomplishments. She will take the world by storm, and so will Eleanore!

J.E., Wisconsin

#### Down Syndrome and ADHD?

J.G. and J.J. (February 1995) are the parents of four-and-a-half-year-old James, who has Down syndrome. Professionals consider James to be very high-functioning, but some feel he may have attention deficit hyperactivity disorder (ADHD). One psychologist has suggested that the use of Ritalin may be appropriate. J.G. and J.J., who describe their son as a "typical class clown," worry that they will be "trading James" playful personality for a better-behaved child."

Our son, Matthew, is almost five and sounds like a double for your James.

We always said Matthew was "hyper," but by the time he was three, we were having a great deal of difficulty coping with his behavior. We tried working with the parent educator at Matthew's early intervention program to develop strategies that would help him. But by the time he turned four, Matthew was totally out of control.

Last spring, we sought help from professionals who had special expertise in behavior modification for children with disabilities. While professionals would not officially classify Matthew's problems as ADHD, we agreed to put Matthew on Ritalin temporarily while we worked closely with the behavior therapist. We started him on the lowest possible dosage (5 mg., twice a day) and never needed to increase it.

Matthew's behavior problems seemed to stem from the fact that he is so high-functioning and has such a great sense of humor. When he "got going," he found it difficult to "turn it off" and relax. We tried Ritalin because he could not control himself enough for behavior modification to work. While it's true he was quieter and a little less "spunky" while on Ritalin, the drug made it possible for us to implement the behavior training.

In September, Matthew started a full-day program at a parochial school for children with special needs. I would give him his first dose of Ritalin in the morning; his teacher gave him the second dose at lunch. One day she forgot to give him the second dose and called me to say that he seemed much more "alert, playful and verbal" than she had ever seen him. We decided to try giving him only the morning dose. He did so well in the afternoons without it, that we eventually discontinued the morning dose as well.

Matthew has been off Ritalin for almost four months now. He is doing wonderfully in school—his teacher has never had a problem with him and probably thinks we are crazy for ever putting him on it in the first place. He constantly comes home with awards and certificates

continued on page 20



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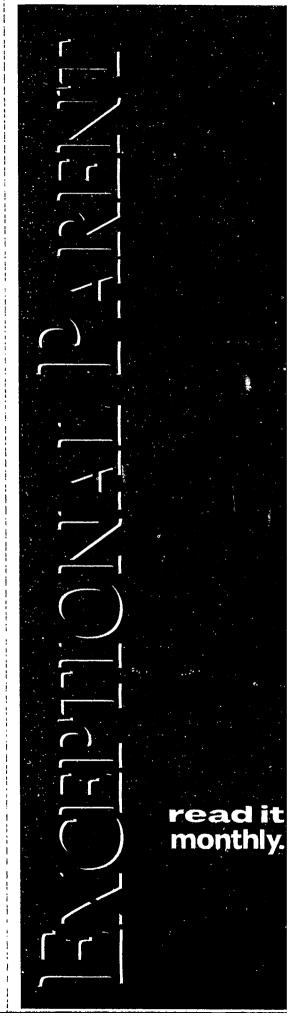
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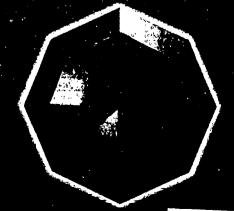


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FLAINE L'CHAO President and CEO United Way of America





AMERICA'S DISABILITY CHANNEL



continued from page 16

for "Student of the Month" and "Student of the Week."

Don't let us mislead you, Matthew is still quite a "bugger" at home, to say the least, but even without the Ritalin. he still responds to behavior modification techniques without the battles we originally encountered.

We feel quite strongly that Ritalin was the answer for us, but only in conjunction with behavior therapy. and certainly not for a long period of time. Because the drug stays in the system for only three to four hours. you can skip a dose-or a whole day if things are going well-without any harmful effects.

L.N. & J.N., Pennsylvania

Encephalocele/Microcephaly

J.H. & T.H. (February 1995) have a two-year-old daughter, Emily, who was born with microcephaly (small head) and an encephalocele (opening in the skull) which was closed surgi-

cally at seven months. Emily subsequenily developed hydrocephalus, a seizure disorder and bilateral optic nerve hypoplasia. J.H. and T.H. were looking for parents of a similar child or anyone else with information on this type of encephalocele.

My seven-year-old daughter, Monica, was born with an occipital encephalocele, microcephaly and amniotic band syndrome (caused by constraint in the uterus and resulting in deformities of her right arm and hand). Her encephalocele was repaired when she was 48 hours old. Happily, she did not develop hydrocephalus, but she has severe mental retardation, cerebral palsy and bilateral optic nerve hypoplasia. She is legally blind and has a seizure disorder.

Monica took her first steps just before her sixth birthday. She now walks independently around our home, however, her balance is not

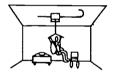
very good. There's no keeping her down, so for her own safety, she needs to wear a crash helmet.

Monica attends an integrated morning kindergarten and an afternoon special education class at our local elementary school. Acceptance by her peers and school staff has been exceptional.

Monica is non-verbal and uses augmentative communication to answer yes/no questions with some success. She also reaches out for objects she wants; for example, she will choose between a cup and bowl to indicate whether she wants to eat or drink. Her school is working on expanding the number of messages she can communicate on her augmentative communication device.

I consider myself very lucky to have Monica in my life. The affection she gives is so pure and without ulterior motives; we should all be that way!

L.P., Connecticut



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Circle # 107

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# **Tom Sullivan**

His parents never took "no" for an answer

Tom Sullivan, 48, is the author of seven books. His autobiography, IF YOU COULD SEE WHAT I HEAR was made into a film in 1982. Sullivan has also appeared on television in "Highway to Heaven," "Fame," "Mork & Mindy" and "WKRP in Cincinnati." He was a special correspondent for ABC's "Good Morning, America" from 1979 to 1982, and has written and produced several films for television. Sullivan's most recent book is Special Parent, Special CIIILD (G.P. Putnam's Sons, 1995; available through Exceptional Parent Library, 800/535-1910), a collection of interviews with six parents of children with disabilities. Sullivan and his wife, Patty, live with their two children in Denver, Colorado.

was born three months premature in 1947 in a hospital just outside Boston. Too much oxygen in my incubator caused a filament to form over the corneas of my eyes, a condition known as retrolental fibroplasia. As a result, I'm

blind. However, blindness may have been the best thing that's ever happened to me. I've enjoyed a world of senses that many people never take the time to appreciate. This appreciation didn't come naturally; it was molded by the love and dedication of my parents.

I cannot imagine

what it was like for my parents to sit in the office of the most famous ophthalmologist of the time and listen while he told them they had a blind son. My mother still quotes him today: "Mister and Missus Sullivan, take him home and



Tom Sullivan Sr. ("Porky") wanted to make sure that Tom Jr. could do and be whatever he wanted.



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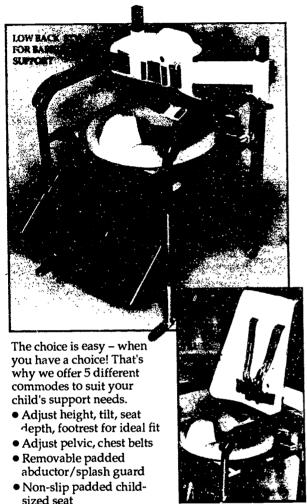
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# COLUMBIA

• EXCEPTIONAL PARENT / APRIL 1995

love him. Or institutionalize him. Those are your only alternatives." My parents chose the first option; they took

me home and loved me.

Recently, my mother has begun to talk about my childhood. It saddens me to hear how painful it was for her to raise a blind child. However, she believed her child should not be limited by his disability.

When I was five years old, I was sent to the Perkins School, a boarding school for blind students less than an hour away from my home in Boston, Every Friday night, my parents



Sullivan attends his daughter Blythe's 21st birthday party, in 1991, with his mother, Marie.

brought me home for the weekend. My mother still talks about the first time they brought me to Perkins: "I watched this little child being taken away by a very kind house person. You got the message that you were not going to be with us and I had to stand there while you kicked and screamed and fought them." Even at five, I understood that if I weren't blind, I wouldn't have had to be at that school. I knew that I wanted to be included with sighted children.

Extracurricular activities were my ticket out of loneliness, and I was blessed with parents who allowed me to become all the things I hoped to be. Whenever my parents were told I couldn't do something, they found a way



Sullivan with (from left) son Tom, wife Patty and daughter Blythe.

to allow me to do it. For instance, once they knew I was musical, they did everything possible to bring music into the house. My father would bring barroom musicians home at night and we'd play Irish songs until four in the morning. Then, he found out that I liked gospel music. Picture a white Irish Catholic father taking his son to a Black church so he could sing gospel music. He didn't care what it took. He just wanted me to be happy.

#### Painful times

My parents did everything possible to make sure I spent my time with children who could see when I was home from school. But no matter how hard they tried, there were moments that were incredibly painful. I would stand in my backyard, listening to the sound of other kids playing baseball down the street. Every time a boy hit his baseball with his bat, I picked up a rock and hit it with a stick.

One day when I was doing this, a kid passed by and shouted, "How you doin', blindey?" At that moment, I knew that he thought of me as different. It hurt.

After that, my father began designing games that I could play with the neighborhood kids—a buzzer on a basket so I could shoot hoops in the driveway; baseball played with a volleyball bounced on the cement, me swinging at the sound.

I also remember the time my father bought me a pony. That summer, I charged a nickel for any neighborhood kid who wanted a pony ride.

### Parents of courage and vision

The hardest concept for a person with a disability to understand is the balance of interdependence: How much can I do alone, and how much help must I ask for? This leads to one of the hardest questions for parents: When do I let go?

My mother remembers my first day at Providence College. After checking in, my parents watched while I tried to find the cafeteria. My mother immediately thought back to the day they had brought me to Perkins: "I cried just like I did when you were five. I didn't want to help too much or be in the way. I had to

watch you struggle in a completely strange place for this independence."

To be fair, I wanted my freedom, but I would have been just as happy to go back home. Freedom is frightening. You want it, you work for it, you scramble to achieve it, but it's frightening. A blind person is limited by the

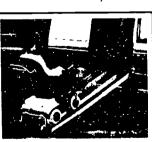
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ircle #101

length of his arm and the length of his stick in a strange environment. Your ears and senses are picking up everything around you, but you know that you're limited by the distance you can reach with your arm and the distance you can touch with that stick. And my parents saw that. "I watched while you asked the first three kids for help," my mom said. "You didn't get it. The kids gave you that kind of 'Oh, I don't know. Go ask somebody else."

#### Special Parent, Special Child

Special Parent, Special Child—a book that I am more proud of than any of my others—focuses on feelings all parents with children of disabilities share. When I first spoke about my childhood with my mother, I realized that although I had often been asked what my parents did when I was a child, no one had ever asked how they felt. After hearing my mother speak about her pain, I wanted to let other parents speak openly, to share all the feelings that no one had asked them about before. I interviewed more than 200 families and chose six that I

felt could express their experiences with the most insight and eloquence. These families were wonderfully candid in discussing the strain of raising a child with a disability.

Speaking with them, it astounded me to learn that the pain and anguish felt by

my parents 47 years ago has not been eliminated, but has only been made sharper by a more complex health system. It was no surprise to discover that parents have strengthened their love for their children and the resolve needed to help them succeed. Caring teachers and school administrators struggle to do a good job with less money and more students. Doctors love and nurture their patients and therapists give of themselves, but they are hampered by a complex and slowmoving health care system. In the end, the success of people like me comes from parents who do not accept "no" as an answer and who are creative, making the most of an environment that contains opportunities for every child with special needs. **EP** 



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# MEDIA

HEN YOUNG
CHILDREN ARE
INJURED:
FAMILIES AS CAREGIVERS IN
HOSPITALS AND AT HOME
by Marilyn Lash, M.S.W.
and Jane Haltiwanger;
M.A., Ed.M., is published by EXCEPTIONAL
PARENT PRESS and is
available through
EXCEPTIONAL PARENT

LIBRARY (800/535-1910). It is the third in a series developed by the Research and Training Center in Rehabilitation and Childhood Trauma, Department of Rehabilitation Medicine, Tufts University School of Medicine, New England Medical Center. The following is an excerpt:

Parents and professionals sometimes disagree over whether it is helpful for parents to be with their child during a painful procedure. Some parents feel that there is no time when their support is readed more and prefer to stay with their child. Some professionals try to involve parents in specific ways to help calm, distract or reassure their child. Others believe that the anxiety and distress of parents can upset the child even more... Decisions must consider the child's age and ability to understand what is happening, a parent's reaction and ability to give comfort or reassurance and a professional's preferences and past experience...

Parents can help professionals during difficult procedures by avoiding negative comments so that the child does not see the professional as the "bad person who did this to me."

Parents can help children build trust in caregivers by helping them understand that sometimes "it hurts for awhile."

#### Limits of parents' power

Young children believe that parents can do just about anything. They are used to being loved, fed, washed and entertained. It is a shock to discover that parents are unable to protect them from pain, take them out of their bandages or traction, or change other



unpleasant parts of their hospital care. If parents choose not to be present during painful procedures, or if they are asked to leave, they still have an important role in comforting the child after the procedure is over.

An injured child needs help to sort out confusing messages about who is in charge, who to trust and what parents can and can't do. Toddlers or preschool-

ers may feel their trust in you has failed. They may be upset when your touch and smiles are not matched with the power to fix things as you have in the past. Build trust again by preparing your child for each new experience. When you pause to explain what will be happening, and it then happens the way you predicted, your child will be comforted and gain some security...

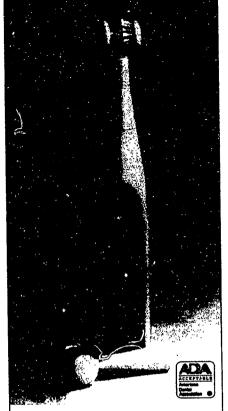
#### Pain and medication

It is very hard for parents to see their children in pain. Many parents feel especially helpless and worried when they must leave. You can help your child by following these suggestions:

- Ask doctors and nurses about the advantages and disadvantages of pain medications and their schedule and doses.
- Help your child during difficult times before medications take effect and when they are wearing off by reading stories, playing games or singing songs. Distraction can lessen pain.
- If your child has unpleasant side effects, such as nausea, confusion, agitation or sleeplessness, report them to the nursing staff or doctor. You and your child may fear that the condition is worsening when changes may be related to medication.
- Communicate for your child. Early signs of pain in facial expressions, sighs or moaning, or muscle spasms may be more readily noticed by you. By reporting them early to staff, you may be able to prevent pain from worsening.
- Discuss back-up plans about pain management and medication in advance. Even if not needed, knowledge of alternatives may help lessen your fears... **EP**

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Young bodies float in a broad expanse of bathtub warm water supported by flotation devices, guided by therapists. There is quiet, affectionate encouragement as contorted limbs loosen and flex, laughter at splashes and water-antics, shared pleasure at accomplishments: reaching out, standing, walking and swimming.

This is hydrotherapy at Berkshire Meadows.

For the boy in our picture above, the intense relaxation of the Hubbard Tank helps to maintain his range of movement. Kept at a water-temperature of 98 to 102 degrees, the butterfly-shaped tank has a seat that can be adjusted to a myriad different angles to accommodate whatever physical disabilities he has. The water is pumped through jets that can focus on any one area of the body, or provide constant high-speed circulation. Not only does this therapy maintain and improve his flexibility; it gives him relief from muscle spasms and pain, and provides sensory stimulation that increases awareness of his body parts. After half-an-hour's hydrotherapy he returns to his classroom calmer, more co-ordinated and more focused. His limbs are more relaxed and have better range of motion than at any other time.

The young woman in the therapeutic pool also et joys a variety of benefits from hydrotherapy. The water is kept at around 94 degrees, and the air temperature in the room just about the same. The pool has a moveable floor, allowing greater flexibility in programming and easy entry and exit. The reduction of gravity's effect enables the youngsters, when in the pool, to move in ways in which otherwise they cannot: when in the water they might walk independently, or might acquire real movement instead of spasticity. Here, in the supportive, liquid warmth, weak muscles are strengthened, blood circulation improved, paralyzed muscles re-educated. Balance, co-ordination and posture are enhanced, and socialization, independence, and self-esteem fostered.

Hydrotherapy is just one part of a multifac_ted program at Berkshire Mead ows, a private, non-profit residential school or children and adolescents who are severely developmentally delayed and may be multiply disabled. Our program includes thorough medical, psychiatric and nursing care, speech therapy and augmentative communication, behavior management, physical therapy and functional communication. An innovative approach to education includes sensory stimulation, self care, and the development of precognitive, cognitive, pre-vocational and independent living skills. We have an open-door visiting policy, with each client's family encouraged to participate in all aspects of their child's program.

ctor, 2523

For further information, please contact: Gail Charpentier, Executive Director, Berkshire Meadows, 249 North Plain Road, Housatonic, MA 01236 (413) 528-2523



SUMMER FUN!

# And We Thought Planning Was the Key

by Nancy Sturm

We thought we were ready. We had stored a full case of youth-sized Attends in a roomy bin in the kitchen of our new RV. We had refilled prescriptions and carefully deposited 10 days' worth of meds in a high cupboard, out of the reach of toddlers. We had laid in a supply of Ensure for David and tapioca for Brenda-life without tapioca would have no meaning for Brenda. We had carefully stockpiled groceries for grownups, favorite treats for toddlers and foods that could be pureed for the non-chewers among us. We had a week's supply of bibs and we had clothing for any type of weather we might encounter. Yes, we were ready...

y husband Bruce and I are experienced campers. As the last of Lour five children left for college, the two of us continued to enjoy weekend and week-long wilderness treks. Our 17-foot canoe carried us and our minimal camping gear to remote and beautiful campsites.

Then, in 1990, the course of our life changed direction. We had volunteered to drive our daughter to Mexico, where she would spend a summer working at a church-operated orphanage for children with disabilities. There, in Northern Baia, we met eight-year-old Brenda. Meningitis at age two had left Brenda with cerebral palsy, a seizure disorder, hydrocephalus and profound mental retardation. After 14 trips to Mexico in a 14-month period, we adopted Brenda and brought her home to Oregon.

The next year, our foster son, David, now 13, came to live with us. David also has cerebral palsy, a seizure disorder, functional blindness, profound retardation and-depending on who's doing the assessment-autism or autistic-like behaviors. We weren't quite Ozzie and

Harriet Nelson, but we now had the ideal American family—a boy and a girl!

Joining the full-hookup crowd

Even veteran campers like us, however, had to recognize that our days of canoe camping had come to an end. First, we replaced our 10-year-old Dodge minivan with an equally well-used Ford one ton-an immense, faded blue van with a lift for the wheelchairs and enough room for five adult passengers.

Next, we found an affordable RV. complete with air conditioning, forcedair heat, stereo, shower, toilet, microwave, VCR and full kitchen. With only the tiniest twinge of guilt, these camping purists had joined the fullhookup crowd.

(Above) Sneaking a kiss: Nancy and Brenda enjoy a relaxing afternoon at the campground. (Right), (From left) Abby's son, Cameron, 4, enjoys an evening around the campfire with Nancy, David, 12, Brenda, 8, and Bruce.

For the maiden voyage of our new RV, we invited our friend Abby and her family to join us, thinking we could share parenting duties so all of us would have a chance to do a little bike riding and hiking. Her husband couldn't get away from work, but Abby jumped at the chance to spend 10 days traveling with four-yearold Cameron and baby Harrison. We added their backpack, stroller and baby jogger to our wheelchairs on the list of essential camping gear.

We gave a copy of our well-planned itinerary, complete with campground phone numbers, to anyone who showed the slightest interest. We were so efficient in our trip planning that we managed to slip in a stop near Portland for a necessary cast change for Brenda, who'd had surgery on both feet a month earlier.

The first campground on our tour was Oregon's Jessie M. Honeyman State Park. Although we couldn't go up onto the dunes that are one of the favorite attractions of this beautiful park, we hiked along the miles of hilly paved paths with David in his wheelchair and Brenda in the baby jogger, which afforded more comfort for her casted legs.

Even a heavy rain the second night





318

110

#### And We Thought Planning Was the Key

didn't dampen our spirits, and in the morning, we packed up as scheduled and drove north along Oregon's rugged central coast to Lincoln City, where we'd planned a shopping stop at a complex of the outlet stores. Bruce pulled the big van and even bigger RV side-by-side in the parking lot, Abby and I fixed lunch for everyone, then Bruce, David and Cameron napped while Brenda, Abby, Harrison and I shopped. We congratulated ourselves. This was the way to camp!

That night we camped at Champoeg State Park, a historic site on the Willamette River offering miles of paved hiking trails. Brenda, usually a good eater, didn't eat well and seemed a little grouchy. Since Abby and I were also feeling a bit grumpy after a long day in the van and a late arrival at our campsite, we weren't particularly concerned.

#### Our perfect plans unravel

The next morning's plan was for Abby and her boys to spend some time with a WHAT HAD HAPPENED TO MY PERFECTLY PLANNED VACATION SCHEDULE? WHY, IF I **NEEDED A VACATION** AND HAD CAREFULLY PLANNED A VACATION, WAS I NOT GETTING A **VACATION?** 

friend of their family while Bruce, David, Brenda and I ran up to Oregon Health Sciences University for Brenda's cast change. Brenda still seemed cranky and, once more, did not eat well. As we drove, she started to vomit profusely and became so limp she could not sit up.

When we arrived at the doctor's office.

Brenda's orthopedist proceeded with the cast change, but had his nurse call the chief of pediatric neurosurgery at University Hospital. By the time her casts were replaced, Brenda had been scheduled for a CAT scan and an evaluation in the neurosurgeon's office. By lunch time, she had been admitted to the hospitalensconced in the very same room she'd occupied a month earlier-and shuntrevision surgery had been scheduled.

My head was swimming. What had happened to my perfectly planned vacation schedule? Why, if I needed a vacation and had carefully planned a vacation, was I not getting a vacation?

#### Unlikely coincidences

Like many Christians, Bruce and I believe that the course of our lives has been ordained by God. And as I sat beside Brenda's bed waiting for an operating room to open up, I began to realize how amazingly fortunate we had been. What an unlikely coincidence that

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319

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Circle #110



David and Brenda look on as Bruce, with baby Harrison on his back, helps four-year-old Cameron with his archery.

allowing Brenda and David varied experiences is more important than wrapping them in cotton wool.

Now we're planning a trip to Mexico for a visit with Brenda's old chums at the orphanage. But this time I'm bringing lots of extra reading material... because you just never know. **EP** 

Nancy and Bruce Sturm live on a farm in Applegate, Oregon with their adopted daughter Brenda, 9, and foster son David, 13. The Sturms also have five grown children, and are hoping to adopt another child with a disability.

Brenda's shunt should fail just as we were driving to the hospital; that the chief of pediatric neurosurgery, whose specialty is shunt revisions, was in and available; that Abby, with her experience in caring for children with disabilities, was with us; and that Bruce had a place to stay while Brenda was hospitalized. I thanked God for the way He had cared for us, but I had to sneak in just the tiniest request that next time. He provide an advance copy of His agenda.

I spent four days of our vacation living in a cramped room on a cot next to Brenda's bed talking quietly with the three other moms lying on similar cots next to the beds of their own daughters, reading whatever I could get my hands on, comforting Brenda and walking back and forth from the hospital cafeteria on the third floor to Brenda's room on the fourteenth.

Abby spent her vacation back at Champoeg State Park, caring for David and her own two boys, and Bruce shuttled back and forth between the hospital and the campground.

On Saturday, Brenda was released from the hospital, and we arrived home in Southern Oregon right on schedule.

Hitting the road again

Were our camping days over? Would Abby ever set foot in our van again? Should we just keep our kids at home where they are safe? We've answered a resounding "no" to all three questions. Since the inaugural voyage of our RV, we've managed several more outings without difficulties. Abby and her family joined us for a return trip to Champoeg State Park to visit the historic sites we had missed before. And we still feel that

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# SUMMER

## **READERS TALK ABOUT: VACATION**

A few months ago, we asked readers to tell us about memorable family vacations. Here are just a few of the stories and

pictures they shared...

# Careful Planning and a Positive Attitude

y husband and I have never been able to agree on the perfect vacation. His ideal vacation is spent sitting quietly in a fishing boat on the Mississippi River. I, on the other hand, love to travel to distant and exciting places. Beginning when all four of our children were young, I began traveling with them by myself.

We took our first major vacation 10 years ago, traveling by train from Iowa to Disney World in Orlando, Florida. Sarah was two years old, Faith was four, Will was eight, and Kevin, who has Down syndrome, was 12.

The day before we left, Sarah was diagnosed as having "failure to thrive with swallowing dysfunction." We were advised to schedule surgery for a gastrostomy tube as soon as possible. To me, "as soon as possible" meant *after* our trip. For now, my mission would be to fatten Sarah up while having fun!

I quickly learned that Amtrak was not as accessible as I had been told. Only one car was wheelchair accessible. Because of this, I had to carry Sarah to the dining car; there were definite advantages to her being underweight!

Kevin wandered off several times, but you can only wander so far on a train. The porters became extremely protective of us—a sort of extended family for the duration of the trip.

I wanted to show the children our nation's capitol during a two-hour layover in Washington, D.C. The Amtrak staff was determined to keep passengers from leaving the train, so we sneaked off. We hailed a cab and told the driver we had \$20 and one hour to see the town. We managed to see many of the sites and still get back to Union Station in plenty of time to reboard.

We had a wonderful week at Disney World. I occasionally left Sarah with a caregiver referred to us through the local Arc chapter. Kevin challenged us daily with his behavior, but I only lost him



World, the Williams children enjoyed breakfast with the Disney characters. Meeting Donald Duck are (clockwise from left rear) Will, 8, Kevin, 12, Sarah, 2, and Faith, 4.

once—on our last day at the park. However, we all managed to find each other in time to return safely home.

#### Return to Disney World

Eight years later, we returned to Disney World; this time we drove. By then, Sarah had many more diagnoses including recurrent pancreatitus, seizures, osteogenesis imperfecta, reactive airway disease and gastrointestinal problems.

Our previous vacations had taught me the value of planning ahead. First, I had to think about Sarah's equipment—feeding pump, formula, bags, syringes for flushing the tube, an extra

tube, diapers, underpads, suction machine and oxygen. I worked with our equipment company, Miller Medical in Coralville, Iowa. They gave me a list of other medical equipment suppliers in case we had a problem during our drive or stay in Orlando.

For our 20-day vacation, we needed 200 diapers and 120 cans of formula. Instead of trying to stuff these supplies into the van, we brought along only what we needed for our days on the road. A week before the trip, we shipped the rest to Florida. The packages were waiting for us upon our arrival.

One of my biggest worries was that Sarah would have a seizure and I would not be able to find her medicine. I put a supply into the overnight bag we used while on the road. I put more in her wheelchair bag, my purse and our lug-

continued on page 34

#### READERS TALK ABOUT:

We invite you to contribute to the discussion in future issues of EXCEPTIONAL PARENT. In upcoming months, readers will be talking about:

- helping a child make friends (July; deadline May 1, 1995)
- experiences with genetic counseling (August; deadline June 1, 1995)
- educational options—special schools or inclusion (September; deadline July 1, 1995)

Write to: Readers Talk, EXCEPTIONAL
PARENT, 209 Harvard St., Ste. 303,
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**EXCEPTIONAL PARENT / APRIL 1995** 

# A Great Scouting O

Troop #767SNess Special Needles S
County, CA, is just like any other box
for one thing—every member has a seminational scheme as a while leading, their partial traditional scheme as a major object termination.

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#### Careful Planning and a Positive Attitude

continued from page 32

gage. I also brought along the original prescriptions of her medications and another for antibiotics in case she got a simple ear infection or strep throat.

I found affordable accommodations at Disney World's Polynesian Resort. Although we paid more for being on-site, it was worth it. We were on the monorail line so all the kids, including Sarah, could come and go easily.

Our insurance company found a nurse for Sarah and paid for one visit a day. This not only gave me a much-needed break, but would also have provided a medical referral if Sarah had needed a doctor.

Sarah celebrated her tenth birthday with Mickey and Minnie and ended up with four complimentary birthday cakes. She couldn't eat a bite, but the rest of us did! To deal with Kevin's challenging behaviors, I had made behavior management charts with rewards for positive behavior. In the end, however, letting him experience the natural consequences of his actions proved more effective. One day, for example, Kevin refused to wear shoes. Then, he decided he could not walk on the hot sidewalk. Faith tried to get him to come along with her, but he was an immovable object, so he missed dinner—an important meal to Kevin.

This summer, I am taking Sarah, Faith and a friend on another trip. I feel sad when I hear families say, "We couldn't possibly take Johnny anywhere, so we all stay home." With careful planning and a positive attitude, anything is possible.

-Mindy Williams Tipton, Iowa



Ready to go: With his carseat secured at one end of the canoe, 22-month-old Jeremy appears eager to travel.

# Due North

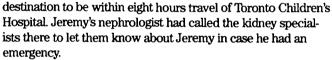
y husband,
Lawrence, and I
have gone
wilderness
camping by canoe since the
beginning of our marriage;
when our children were
born, it seemed natural to
include them in these trips.
Our two older children were
"on the water" before each
was 18 months old. When our
third child, Jeremy, arrived,

we didn't hesitate to take him along, too. However, Jeremy was born with developmental delays, hypotonia, nystagmus, kidney disease and slow growth. In planning for any trip, we knew we would need to balance his safety with our fun.

We decided that a short trip within safe distance of a major hospital would satisfy both needs. Over Labor Day weekend in 1993, we camped at the Algonquin Provincial Park, 350 miles due north of Toronto, Ontario. Jeremy was 22 months old; Jonathan and Ashley were 11 and 9.

Wilderness camping means being completely dependent on the contents of your canoe. We planned extra carefully to be sure we didn't forget any of Jeremy's medications, formula or food. We chose our

With Jeremy on his back, Lawrence Gaia enjoys a wildemess hike with children Ashley, 9, and Jonathan, 11.



After driving to the park, we paddled 10 miles on the lake to a rustic, unimproved campsite. Jeremy wore a life vest and sat in his car seat, which we lashed to the thwart (horizontal support) of the canoe. He really enjoyed the movement of the waves and watching the loons and ducks floating on the water. Our biggest problem was keeping him from leaning over the edge of the canoe to run his fingers in the water. His big brother had to steady him several times to keep him balanced in the boat.

At the campsite, we put up the tent. Jeremy used his own "Mickey Mouse" sleeping bag and, after one restless night, slept soundly. We had to pack in clean diapers and pack out dirty ones. We did diaper changes on a changing pad laid out on the ground. Cooking was done over a campfire or portable camp stove. Cleaning out baby bottles was a bit of a chore. We drew water from the lake and boiled it to wash bottles and dishes. Food was put into duffel bags and hung high on tree branches to keep bears and raccoons from eating it.

Jeremy thrived on the constant attention he received. Without the distractions of television, radio, school, therapy visits and doctor's appointments, our family had only each other for entertainment. We did a lot of talking, singing, working and fishing together. Though severely delayed in verbal skills, Jeremy added several words to his vocabulary during the trip. He was very inquisitive about his surroundings and explored by crawling around the campsite on his hands and

knees—much to Mom's dismay when she did the laundry at home!

The extra work and planning were well worth having Jeremy along. His enthusiasm and curiosity helped us all re-experience the awe and wonder of our first trips into the unspoiled wilderness. We can't imagine life or a vacation without him.

-Paulette Gaia Chesterland, Ohio





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Circle # 31

A Disney Birthday

ur planning for Christopher's sixteenth birthday began when he turned 15. Christopher's disabilities include cerebral palsy, a seizure disorder and profound mental retardation. He does not speak or walk independently. Christopher lives in an intermediate care facility and makes frequent home visits.

We (Christopher's mom, Glynnis Rea, and myself, his godmother) wanted Chris to celebrate his sixteenth birthday in a world we knew was special for him. We spent a year preparing him for the birthday celebration he would have at Disney World in Orlando, Florida.

The highlight of Chris' birthday celebration came in Fantasyland at the Magic Kingdom where he met the girl of his dreams-Snow White. The Snow White story has long been one of his favorites, and we told Chris he would meet her at Disney World.

Chris can walk with assistance, but does not have the ability to stand alone. But when he saw Snow White, Chris indicated that he wanted to get out of his wheelchair. With help, he walked over to Snow White and beamed as she was introduced to him. She talked to Chris for several minutes, then kissed him on the cheek. Wow! What a birthday!

The accommodations at Disney's All-Star Music Resort



Christopher Limpar, 16, meets Snow White, the girl of his dreams.

were wonderful. Our room had an accessible bathroom and was within walking distance of a food court, gift shop, game room and swimming pool. Wheelchair-accessible shuttle buses to and from the theme parks ran every 20 minutes. The attentiveness of Disney employees to our needs made our vacation even more memorable.

The First Aid and Baby Care Stations at each of the theme parks (Epcot, MGM Studios and the Magic Kingdom) were invaluable. They were equipped with private rooms and

kitchens with microwave ovens where we were able to prepare Chris' puréed diet, feed him and attend to his personal needs.

We didn't realize how much stamina Chris had until the Disney trip. We arrived at the parks around 10 each morning and usually stayed until closing. Chris e pecially enjoyed Epcot Center where he rode Spaceship Earth, the Journey into Imagination, the Universe of Energy and many more rides. At the World Showcase he ate his birthday dinner in Mexico, had dessert in France and did his souvenir shopping in Canada.

Our success was definitely due to the planning we did and the time we took to prepare Christopher for his magical adventure.

-Alice E. Mudge Alice Mudge lives in Germantown, Pennsylvania. Christopher's mother, Glynnis Rea, also contributed to the writing of this story.

#### **Preparation is Key**

Although our planning was specific to Disney World, similar strategies could be used by families planning other trips:

• Disney World's free Guidebook for Guests With Disabilities provides an overview of special services and accessible facilities, particularly for individuals using wheelchairs. Our copy of the Guidebook helped us plan more effectively.

 We familiarized Chris with the theme parks he would be visiting by having him watch a vacation planning video about Disney World during his home visits.

 Chris listened to audiotapes featuring Disney characters he was likely to meet and music he was likely to hear.

• The day before we left, we brought Chris to the airport to watch planes taking off and landing. We explained boarding procedures to him.

• We worked closely with a travel agent to ensure that our needs were met. We booked seats close to the plane's door for ease in getting Chris on and off the plane. His wheelchair was "gate-checked" and put in the cargo section of the plane. A crew member brought it to the door of the plane immediately after landing.

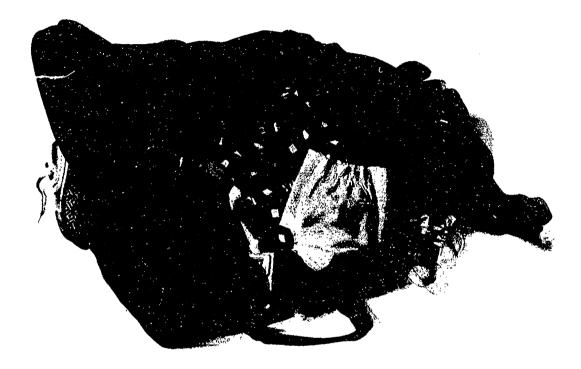
• We requested accessible accommodations at Disney's hotels and asked specific questions prior to making a reservation to ensure that the room would accommodate our needs.

We brought extra medication with us on the plane in case of delays.

• Timing was crucial. We made the trip in February because Chris does not tolerate extreme heat.

# He's never gone on a sleepover before because he wets the bed.

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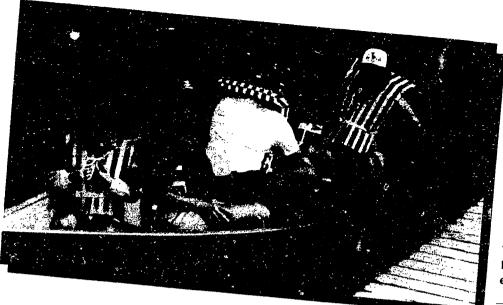
your pediatrician. You could be in for some good news. But one thing is absolutely certain. Your child *will* outgrow bed-wetting.

In the meantime, use GoodNites.



GoodNites mean Good Mornings





An afternoon on the lake: (From left) Jonathan Moran. Theresa Moran, Daniel Hawkins. Mathew Moran and James Moran enjoy canoeing at Camp Glen Spey.

# **Family Camping**

or the last five years, we have gone on an annual camping trip with several other families. When we invited these other families to share our first family camping trip to Camp Glen Spey, a Girl Scout camp in Glen Spey, New York, most had not been camping before.

These were people that we knew well. We knew their standards of behavior for themselves and their children. We knew that they were tolerant of our children and that we were tolerant of theirs.

On that first trip, eight adults and 13 children, aged two to 14, spent at least part of a five-day period at the camp. Four of the children had disabilities, including attention deficit hyperactivity disorder (ADHD), learning disabilities, low vision and arthritis. Each child had at least one friend his or her own age, which the children said was one the best things about the trip.

A week before the trip, we had an organizational meeting to outline procedures, rules and routines. We talked about the chores each person would do and planned meals, taking special dietary needs into consideration.

We chose to stay in a large cabin instead of tents. This made it easier to store food and medication. The cabin was no more than 200 yards from anywhere we needed to go. It had a main room with 20 cots, several tables and chairs, a wood stove and a fireplace. There was a phone connected to the site director's lodge and the ranger's house. We parked our cars next to the cabin so they would be available in case of an emergency.

Since we had no fewer than five adults at camp at any time, we were able to supervise all the activities at one time. The children were required to use the buddy system: no one could be alone at any time. As long as they were with their buddies, however, they could go to any activity

site where there was an adult. The children could spend as much time as they wanted at each activity.

Although closely supervised, the children felt independent. All the adults shared child care—and we even got some precious time to ourselves. The teens also helped to supervise smaller children; they understood that safety was everyone's responsibility.

The waterfront offered swimming, rowboats, canoes, kayaks, inner tubes and sailboats under the supervision of a certified water safety instructor.

We did have to adapt some activities for our children. For example, Jon and Matt were not strong enough to paddle the kayaks. However, with the kayak tethered and an adult nearby, we let them ride in and paddle the kayaks just outside the wading area.

We went on a hike and had a scavenger hunt. Instead of collecting things during the hunt, we used our senses to explore the woods-the textures, sounds, smells and sights. The hike was purposely short and ended at a gravel path so we could have a car available for those who were too tired to walk back to the cabin.

After each night's dinner, we lit a campfire. We sang and told stories—but no ghost stories! As each child fell asleep, we carried them into the cabin and put them to bed. The older children stayed up later. Once they were also in bed, the adults had some quiet time to themselves under a starry sky within a few feet of the sleeping children.

These trips have been our family's favorite and most relaxing vacations. Sharing chores, especially child care, makes it possible to have some much-needed time off. The slow pace, flexible schedule and choice of activities have made these trips successful.

> -Theresa and James Moran Ridgewood, New Jersey



# Surf's Up!

rian loves the beach. With a PVC-pipe beach buggy we have made ourselves, Brian is able to enjoy walks on the beach and getting splashed by the waves.

Brian, 11, has lissencephaly and cerebral palsy. He is unable to sit or stand unsupported. Brian uses a custom-built wheel-chair that provides lateral and head support.

We started building equipment for Brian years ago when we could not find certain equipment, or when the commercial alternatives were too expensive. One of our most successful early projects was an "all-terrain vehicle." We started by building a PVC-pipe chair frame modeled after the seat portion of his wheelchair. The chair's back and seat were made of plywood, cushioned with foam and covered in canvas. We bolted it into a Little Tikes plastic wagon with wide wheels that went well over gravel, dirt and grass.

Best of all, we discovered that our home-built vehicle also rolled along great on a sandy beach! We started taking vacations in Cape May at the New Jersey shore where we eventu-

Mom Helen and "beach bum" Brian enjoy the beach at North Cape May, New Jersey. ally bought a summer home.

Many of the Cape May beached are accessible—ramped down to the sand. (Several adult-size beach wheelchairs are also

available and might be useable by children with good trunk control.)

After five years, Brian outgrew this first wagon. That is when we made our newest beach buggy. It was a family project with Brian assisting from his prone stander, now re-named "Brian's workbench." The new buggy has an all-PVC frame with large, fat, garden-cart tires. The seat, back and footrest are made from the same kind of vinylcoated nylon webbing that is used for lawn furniture. The chair comes off the wheel base so

Brian can also use it around the house.

The best feature of this beach buggy is that it is completely waterproof. We can walk the buggy right into the water and let the waves splash over us. Brian likes to "jump waves" with his dad.

Brian always smiles when someone stops us to ask about his buggy. He is proud that he helped to build it, and he really likes being able to enjoy so many once-inaccessible places.

-Helen and Joe Markee Franklin, Massachusetts

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# Sharing the World with Our Children

ur two-year-old son's diagnosis with a rare disorder sent us into a tailspin—surgeries, specialists on both coasts and trying to make sense of all the changes this diagnosis meant for Ezra, for the two of us and for the rest of our family.

Through it all, we held on to a very strong desire to travel again. Traveling had been an important part of our marriage and we did not want to lose all sense of our previous life. We found the answer in cruises.

Both our son and daughter have disabilities. Ezra, now 5, has familial dysautonomia (FD), a genetic disease occurring primarily in Jews. FD causes dysfunction of the autonomic nervous system, which controls such bodily functions as blood pressure, body temperature, swallowing and digestion. The condition also affects sensory abilities. Individuals with FD may have a decreased or absent reaction to pain and a lack of taste buds. Unrelated to FD, both Ezra and Eliana, 8, also have a deletion of the short arm of the eighth chromosome.

When planning a cruise, we always have our travel agent inform the cruise line about our family's special needs. This prepares them to make accommodations. When we arrive at the dock, the ship's staff is waiting to help us carry Ezra's medical equipment onto the ship. They always make sure we can board immediately and do not have to wait in line for documents.

Dietary needs are a constant concern for us. Eliana is highly allergic to all dairy products. Ezra is fed every night by a gastrostomy tube; he can eat some food, but rarely drinks by mouth. Shortly after boarding a ship, we give the head chef a detailed list of the foods our children can and cannot have. Kitchen staffs have been very accommodating in meeting our children's special food needs and have always made food avail-

able if a meal is missed or medical needs interfere.

Cruise ships always sail with a full medical staff. We make sure we meet the doctor and know the location of the ship's medical center. Fortunately, we have needed medical attention only once.

Ezra participates in all the activities planned for kids—even if that means joining a group of slightly younger children in order to keep up and be able to rest when he gets tired.

Eliana and Ezra clown around with dining room waiter David.



**Ail aboard!** Gary and Georgia Freedman-Harvey, with children Eliana, 7, and Ezra, 4, board the cruise ship Viking Serenade during a 1993 family vacation.

During our last cruise, Ezra and Eliana were determined to enter the talent show. Even though Ezra was just learning to sing, and only sang every other word, our kids were the stars of the show. They received medals and lots of applause; Ezra's pride lasted for weeks.

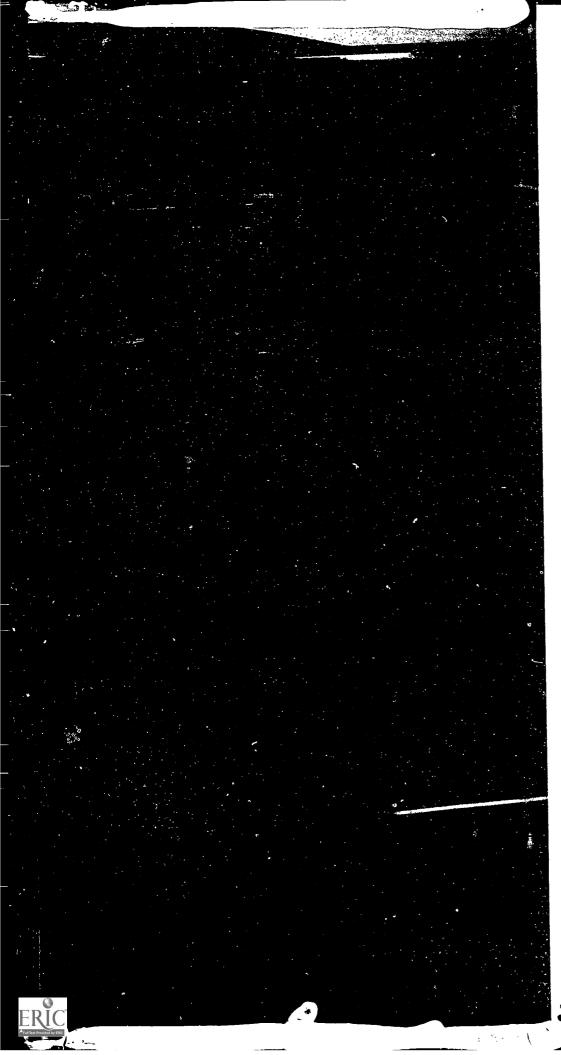
A cruise ship offers plenty of room for moving around. When Ezra isn't feeling well, we push him in his cruiser to a spot on deck where things are happening. That way he still feels that he is part of the action. During visits to various ports, one of us can al. rays return to the ship with Ezra, while the other contin-

ues sightseeing with Eliana. Neither of us ever feels like we are stuck in a hotel room at any time

We look forward to going on longer cruises with our children. It is one way we can let our son see the world and participate in the fun of travel. Travel is an important part of the way we educate and have fun with our children. While we may not be able to travel to the most exotic and isolated spots, we can still share the world with our children.

-Georgia and Gary Freedman-Harvey Seal Beach, California





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330

#### TRAVEL RESOURCES



#### **ORGANIZATIONS**

MOBILITY INTERNATIONAL USA Mobility International USA (MIUSA) is a non-profit organization dedicated to equal opportunities for persons with disabilities in international educational exchange, leadership development, disability rights training, travel and community service. Since 1981, MIUSA has offered international educational exchanges for individuals with and without disabilities-including teenagers-from more than 20 countries. Program participants take part in leadership training, disability rights awareness, cross-cultural education and language classes. Applications are now being accepted for upcoming 1995 exchanges in Azerbaijan, Mexico, Russia and Eugene, Oregon. MIUSA publications include A New Manual for Integrating Persons with Disabilities into International Exchange Programs (\$16 for MIUSA members, \$18 for non-members; includes shipping) and A World of Options for the 90's: A Guide to International Educational Exchange, Community Service and Travel for Persons with Disabilities (\$14 for MIUSA members, \$16 for non-members; includes shipping). MIUSA also offers videos, a quarterly newsletter, Over the Rainbow, and travel information for members. To join MIUSA, or for an exchange application, contact P.O. Box 10767, Eugene, OR 97440, (503) 343-1284 (V/TTY), (503) 343-6812 (fax).



TRAVELIN' TALK Founded by Rick Crowder, an Air Force veteran with a disability, Travelin' Talk is a network of peo-

ple and organizations who are willing to provide travelers with disabilities with information before and during their trips. Travelin' Talk spans the globe with resources, offers of help and information people with disabilities may need-all available over the telephone. A complete listing of members, the information they can offer and their phone numbers is compiled in The Travelin' Talk Directory. available through Exceptional Parent Library, (800) 535-1910; \$32.50. Travelin' Talk also publishes a quarterly newsletter that includes updates of the member list, new travel resources, travel tins and stories about the ways members are helping travelers with disabilities. Subscriptions are available with any size donation to Travelin' Talk, Other services include listings of resources such as van rentals, accessible lodging, travel/tour agencies specifically for persons with disabilities and other organizations who can help travelers. For more information, contact Travelin' Talk, P.O. Box 3534, Clarksville, TN 37043, (615) 552-6670 (voice), (615) 552-1182 (fax).

#### **PUBLICATIONS**

#### Books

ABLE TO TRAVEL: TRUE STORIES BY AND FOR PEOPLE WITH DISABILITIES

Edited by Alison Walsh with Jodi Abbott and Peg L.

Smith; Rough Guides, Ltd. (1994)
 More than 100 articles by travelers with various disabilities. Information on transportation, food, lodging,

costs, and attractions from Amsterdam to Zimbabwe. Organized by country, 603 pp.

• Available in the U.S. from: Penguin Books, 37

Hudson St, New York, NY 10014, (212) 366-2000 (voice); \$21.95 (includes shipping).

#### ACCESS TRAVEL U.S.A.

Creative Hospitality Concepts (1994)

Quick-reference book, easy-to-use

chart format. More than 800 listings of cruise ships, hotels and resorts.

information and organization

resources, ski areas and transportation providers; national directory of

TTY numbers. Each listing features accessibility data including number of

adapted rooms/cabins, automatic doors and eleva-

• tors; room, bath, shower and door dimensions; and

dining and public facility information including table height and Braille menu availability. 176 pp.

Available from: Exceptional Parent Library, (800)

**535-1910; \$19.95.** 

they've headed safaris in their neighborhood park, and pondered the panthers and pythons, then probed along the surface of Mars in their trusty all-terrain vehicles. They've recovered the last of the golden keys while their computer proclaims them heirs to the realm. Kid Power™ is for kids making tracks. A child's tool, like a child's toy must be durable and adaptable, allowing them the freedom and range. Jennings Everest** to explore their environment creatively and independently. Kid Power™ is tough and reliable with a unique styling that adjusts to your child's changing needs. Kid Power™ is easy to program, with precision controls, accessible battery boxes, controlled tracking, a rugged steel frame and a host of options that allow kids to assert their individuality and Westyle.



Circle #207

#### FODOR'S GREAT AMERICAN VACATIONS FOR TRAVELERS WITH DISABILITIES

Fodor's Travel Publications (1994)
Guide to cities, parks and campgrounds for travelers
with mobility, hearing and vision impairments. Very
detailed accessibility information for restaurants,
hotels and attractions. 600 pp.

• Available from: Exceptional Parent Library, (800) 535-1910: \$18.00.

#### HANDICAPPED IN WALT DISNEY WORLD: A GUIDE FOR EVERYONE

By Peter Smith; SouthPark Publishing (1993)
Focus on mobility, but also addresses other disabilities and special health care needs. Includes travel options to and within Orlando; planning tips; detailed descriptions of hotels, airlines, rides and costs; maps. Resources arranged by specific disability. 293 pp.

 Available from: SouthPark Publishing Group, 4041 W Wheatland Rd, Ste 156-359, Dallas, TX 75237, (800) 669-5657, (214) 296-4686 (fax); \$13.95 (includes shipping).

### WHEELS & WAVES: CRUISE, FERRY, RIVER & CANAL BARGE GUIDE FOR THE PHYSICALLY HANDICAPPED

By Genie and George Aroyan; Wheels Aweigh Publishing Company (1993)

Individual passenger vessels are described in terms of wheelchair accessibility, diagrams and deck plans; organized by type of boat and region of the world. Includes tips on sailing, canoeing and rafting; local resources; and ADA regulations related to water travel. 173 pp.

 Available from: Wheels Aweigh, 17105 San Carlos Blvd, Ste A-6107, Ft Myers Beach, FL 33931; \$11 (includes shipping).

#### **Newsletters**

#### THE DIABETIC TRAVELER

Quarterly, Each issue focuses on a different topic.

• Diabetic Traveler, PO Box 8223-RW, Stamford, CT 06905, (203) 327-5832, \$18.95/year.

#### HANDICAPPED TRAVEL NEWSLETTER Bi-monthly. All aspects of travel.

 Handicapped Travel Newsletter, PO Drawer 269, Athens, TX 75751, (903) 677-1260 (wice/fax), \$10/year.

Over the Rainbow See: Mobility International USA under Organizations.

#### TIDE'S IN

Quarterly newsletter of Travel Industry and Disabled Exchange (TIDE). Information on international accessibility, transportation, hotel accommodations and national and international tours.

• TIDE, 5435 Donna Ave, Tarzana, CA 91356, (818) 343-6339; \$15/year.

Travelin' Talk Newsletter See: Travelin' Talk under Organizations.

#### Other Publications

#### Access Travel: AIRPORTS

Contains charts on accessibility features of individual airports in all parts of the world. Published 1993. Free.

#### New Horizons for the Air Traveler with a Disability

Explains rules and guidelines governing airline travel and airport accessibility. 33-page booklet; 50¢.

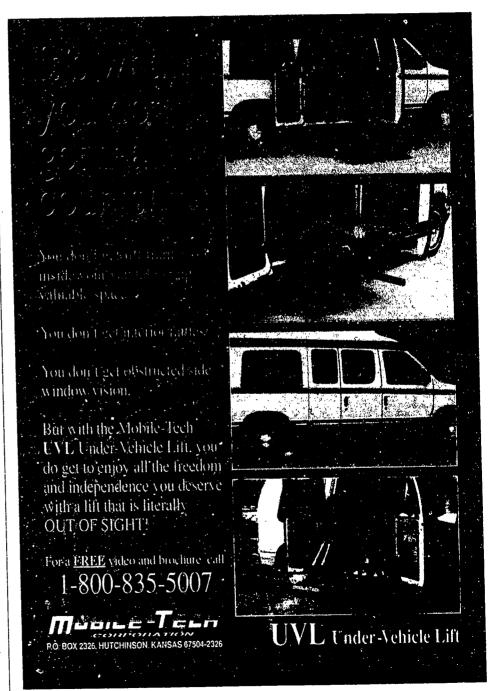
• Available from: Consumer Information Ctr, Dept 389B, Pueblo, CO 81009. (202) 501-1794.

#### TIPS FOR TRAVELING WITH DISABILITIES

Travel tips and listings for tours, travel agencies and resources for travel information (including many large-print books and books on tape). Focus on U.S. 30 pp.

 Available from: Information Ctr for Individuals With Disabilities, 27-43 Wormwood St, Boston, MA 02210, (800) 462-5015 (V/TTY; MA only), (617) 727-5540, (617) 345-9743 (TTY), \$10 (includes shipping). Virtually every airline in America now uses the Columbia AlsleMaster Boarding Wheelchair, a highly maneuverable, extranarrow chair designed for use in confined spaces. The chair may be rolled or, when necessary, carried up and down stairs. For information, contact Columbia Medical Mfg., P.O. Box 633, Pacific Palisades, CA 90272, (800) 454-6612 (volce), (310) 305-1718 (fax). Columbia's Internet address is CMedOnline@aol.com.









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#### Circle #69

#### TRAVEL RESOURCES

#### **Hotels and Motels**

Major hotel and motel chains can provide Information about accessibility at individual properties. Most will also send free brochures with accessibility information.

Adam's Mark: (800) 444-2326

Best Western: (800) 528-1234 (voice), (800) 528-2222 (TTY)

Budget Host Inns: (800) 283-4678

Clarion: (800) 252-7466, (800) 228 3323 (TTY)

Colony: (800) 777-1700

Comfort: (800) 228-5150, (800) 228-3323 (TTY)

**Compri:** (800) 426-6774, (800) 528-9898 (TTY)

**Days inn:** (800) 325-2525, (800) 325-3297 (TTY) **Doubletree:** (800) 528-0444

, (800) 528-9898 (TTY) Econo Lodge: (800) 446-

6900, (800) 228-3323 (TTY)

Embassy Suites: (800) 362-2779, (800) 458-4708 (TTY)

Fairfield Inn: (800) 228-2800, (800) 228-7014 (TTY)

Forte: (800) 225-5843

Four Seasons: (800) 332-3442

Friendship Inns: (800) 453-4511, (800) 228-3323 (TTY)

Hilton: (800) 445-8667, (800) 368-1133 (TTY)

Holiday Inn: (800) 465-4329, (800) 236-5544 (TTY)

**Hyatt Hotels & Resorts:** (800) 233-1234, (800) 228-9548 (TTY)

Inter-Continental: (800) 327-0200

La Quinta: (800) 531-5900, (800) 426-3101 (TTY)

Leading Hotels of the World: (800) 223-6800

Marriott: (800) 228-9290, (800) 228-7014 (TTY)

Meridien: (800) 543-4300, (800) 441-2344 (TTY)

Motel 6: (505) 891-6161, (505) 891-6160 (TTY)

Nikko International: (800) 645-5687,

(800) 255-2880 (TTY)

Omni: (800) 843-6664

Quality Inn: (800) 228-5151, (800) 228-3323 (TTY)

Radisson: (800) 333-3333

Ramada: (602) 389-3800 , (800) 228-3232 (TTY)

Red Lion: (800) 547-8010

Red Roof Inns: (800) 843-7663, (800) 843-9999 (TTY)

Ritz-Cartton: (800) 241-3333

Rodeway: (800) 228-2000, (800) 228-3323 (TTY)

**Sheraton:** (300) 325-3535, (800) 325-1717 (TTY)

**Sicep Inn:** (800) 221-2222, (800) 228-3323 (TTY)

**Stouffer:** (800) 468-3571, (800) 833-4747 (TTY)

**Super 8:** (800) 848-8888, (800) 533-6634 (TTY)

**Travelodge:** (800) 578-7878

Westin Hotels & Resorts: (800) 228-3000, (800) 221-

8818 (TTY)

Accessibility at some

Holiday Inn hotels

include wide door-

showers. Pictured is

Holiday Inn's Crowne

ways and roll-in

Plaza Ravinia in

Atlanta, Georgia.

.ioto courtesy

**Embassy Suites.** 

**Wyndham Hotels & Resorts:** (800) 822-4200, (800) 441-2344 (TTY)

#### Van Rentals

While vacationing, many families need to rent wheelchair-accessible vans or automobiles that are large enough to accommodate needed equipment.

Some national car rental companies can provide accessible vehicles in some locations, but two leading rental companies specialize in vehicle rentals for people with disabilities:

Wheelchair Getaways: More than 85 locations throughout the U.S. and Puerto Rico. Offers full-size vans with wheelchair lifts or ramps, tie-down systems, raised roof or lowered floors and seating for up to four other passengers. Mini-vans and electric scooters

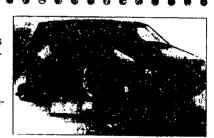


Photo courtesy Wheelers Accessible Van Rentals, Glendale, AZ.

available at some locations. Some vans equipped with hand controls.

Wheelchair Getaways, P.O. Box 605, Versailles, KY 40383, (800) 642-2042, (606) 873-8039 (fax)

continued on page 46

K

# Me Make Seizures A Litte Less Scary ....

# Aleliu tand Toliuse Who



Epilepsy Foundation of America.

4351 Garden City Drive Suite 500 Landover, MD 20785

(301) 459-3700 or (301) 577-9056 (FAX)

### **Membership Reservation Form**

<del>334</del>

#### TRAVEL RESOURCES

continued from page 44



Photo courtesy Wheelchair Getaways, Versailles, KY

#### • Wheelers Accessible Van Rentals:

73 locations throughout the U.S. Offers accessible Chrysler mini-vans with lowered floors and automatic tuck-away ramps with seating for two wheelchair users and five other passengers. Electric scooters available. All vans can be equipped with hand controls if needed.

Wheelers Accessible Van Rentals, 7101 N. 55th Ave., Glendale, AZ 85304, (800) 456-1371, (602) 435-9989 (fax)

Call rental companies several weeks in advance to make sure they have what you need. Company representatives in many locations can provide information about local attractions and accessible accommodations. They may also provide advice on packing wheelchairs and other equipment for air travel.

-Marc S. Malkin

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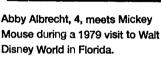
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## The Ultimate Playground: Amusement Parks

by Donna G. Albrecht

ertainly the ultimate playground is an amusement park because it combines all types of sensory stimulation. Whatever your child's level of physical ability, there will be new sights, sounds, smells and sensations to thrill her. Many parks have active attractions like rides and more passive attractions like stage shows. Plan to keep a balance so neither you nor your child become overly exhausted.

if you have any questions about whether a particular ride is safe and appropriate, ride it alone once to determine if it is safe for your child. For instance, a ride that exerts strong "G" forces as it swings in circles may cause you to slide on the seat. Ascertain if you can hold your child safely without her slipping or getting a body slam





Disney World in Florida.

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- > Start now to access more of life.
- ➤ Experience what you want, when you want it... friends, family, entertainment. You Choose!
- Select vehicles equipped with hand controls.
- ➤ Call today to rent one of our fully equipped, wheelchair accesssible, full sized or mini vans. Serving over 80 cities in the Continental U.S. and Puerto Rico.



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Circle #215

from you as you slide.

For children who are physically weak, the safest rides are normally the ones that do not need safety restraints, such as merry-gorounds and any ride where you are completely enclosed in a seating container that moves gently. If you are considering taking your child on a thrill ride such as a roller coaster, talk with your doctor or physical therapist first and, if you must make an immediate decision, err on the side of caution.

**Avoiding lines** 

Many parks have special entrances to rides and attractions for families with a child who has a disability. Cften you can bypass the long lines and be accommodated almost immediately. However, some parks now have a policy that only one person may accompany the child. Others have to go through the line and you will all be accommodated when they reach the front of the line. In theory, it makes sense, but it can be pretty boring for the person who spends most of the day alone standing in line. Check with the park about its regulations before you go.

Meeting restroom needs

In all likelihood, the park will have some extra-large restroom stalls marked for people who have disabilities. However, if your particular equipment and maneuvering needs do not permit you to use these stalls discreetly, help is usually available. Look for a nursing or first-aid station. It should have a bathroom and/or private area with beds and bedpans where you can help your child with her toileting needs. The staff may be willing to lend a hand if you need help.

Excerpted with permission from RAISING A CHILD WHO HAS A PHYSICAL DISABILITY by Donna G. Albrecht (John Wiley & Sons, Inc., 1995); available through Exceptional Parent Library, (800) 535-1910; \$12.95.

### TRAVEL RESOURCES

#### Theme Farks

Many theme parks offer free detailed guidebooks for visitors with disabilities. Some also offer discounts for visitors with disabilities. Accessibility services provided by each theme park are coded by number and follow each listing. Numbers correspond to items listed in the Key to Services.

#### Adventure Island

P0 Box 9158 Tampa Bay, FL 33674 (813) 987-5600 (voice) (813) 987-5443 (fax) 1,3,5,6,7,12,13

#### Busch Gardens Tampa Bay

P0 Box 9158 Tampa Bay, FL 33674 (813) 987-5000 (voice) (813) 987-5443 (fax) 1,3,5,6,7,12,13

#### Busch Gardens Williamsburg

1 Busch Gardens Blvd Williamsburg, VA 23187-8785 (804) 253-3350 (voice) (804) 253-3399 (fax)

#### Disneyland

1.2.3.5.6.7.12.13

c/o Information 1313 Harbor Blvd Anaheim, CA 92803 (714) 999-4565 (voice) (714) 999-4569 (TTY) (714) 490-3223 (fax) 1,2,3,4,5,6,7,8,12

#### Hersheypark

100 West Hersheypark Dr Hershey, PA 17033 (717) 534-3900 (voice) (717) 534-3830 (TTY) (717) 534-3165 (fax) 1.2.3.4.5.6.7.10.12.13

#### Oceans of Fun/Worlds of Fun 4545 Worlds of Fun Ave

4545 Worlds of Fun Ave Kansas City, MO 64161 (816) 454-4545 (voice) (816) 454-4655 (fax) 1,2,3,5,6,7,12,13

#### Sea World of California

1720 South Shores Rd San Diego, CA 92109 (619) 226-3929 (voice) (619) 226-3953 (fax) 1,2,3,5,6,7,8,12,13

#### Sea World of Florida

7007 Sea World Dr Orlando, FL 32821 (407) 351-3600 (voice) (407) 345-5268 (fax) 1.2.3.6.7.8.9.12.13

#### Sea World of Ohio

1100 Sea World Dr Aurora, 0H 44202 (216) 562-8101 (voice) (216) 995-2185 (TTY) (216) 995-2119 (fax) 1,2,3,4,5,6,7,11,12,13

#### Sea World of Texas

Sea wond or lexas 10500 Sea World Dr San Antonio, TX 78251 (210) 523-3000 (voice) (210) 523-3199 (fax) 1.23,5,6,7,9,12,13





#### Sesame Place

100 Sesame Rd Box L579 Langhome, PA 19047 (215) 752-7070 (voice) (215) 741-5307 (fax) 1,3,5,6,7,12

#### Six Flags Great Adventure

Rte 537 Jackson, NJ 08527 (908) 928-2000 (voice) (908) 928-2775 (fax) 1,2,3,5,6,7,12,13

#### KEY TO SERVICES

- 1 Accessible restrooms
- 2 Accessible telephones/TTYs
- 3 Accessible restaurants
- 4 Accessible hotels/motels
- 5 Accessible rides/attractions
- 6 Accessible parking7 Wheelchair rentals
- 8 Sign language interpreters
- 9 Braille information guides
- 10 Wheelchair repair services
- 11 Personal care services
- 12 Guide dogs permitted13 Guidebooks for visitors with disabilities

#### SUMMER FUN!

#### Six Flags Great America

P0 Box 1776 Gurnee, IL 60031 (708) 249-1776 (voice) (708) 249-2390 (fax) 1,2,3,5,6,7,12,13

#### Six Flags Magic Mountain P0 Box 5500

Valencia, CA 91385 (805) 255-4100 (voice) (805) 255-4815 (fax) 1,2,3,5,6,7,12,13

#### Six Flags Over Georgia

PO Box 43187 Atlanta, GA 30378 (404) 948-9290 (voice) (404) 948-4378 (fax) 1.2.3.5.6.7.12

#### Six Flags Over Mid-America

MIG-America PO Box 60 Eureka, MO 63025 (314) 938-5300 (voice) (314) 938-4805 (TTY) (314) 587-3617 (fax) 1.2.3.4.5.6.12

#### Six Flags Over Texas

P0 Box 191 Arlington, TX 67010 (817) 640-8900 (voice) 1,2,3,5,6,7,12,13

#### **Universal Studios Florida**

Guest Relations 1000 Universal Studios Plaza Orlando, FL 32819 (407) 363-8000 (voice) (407) 363-8265 (TTY) (407) 363-8660 (fax) 1,2,3,5,6,7,8,12,13

#### **Universal Studios Hollywood**

100 Universal City Plaza Universal City, CA 91608 (818) 508-9600 (voice) (818) 752-8514 (TTY) 1,2,3,4,5,6,7,8,13

#### Wait Disney World Resort

(Epcot, Disney-MGM Studios and Magic Kingdom) PO Box 10,000 Lake Buena Vista, FL 32830 (407) 828-1258 (voice) (407) 345-5984 (TTY) (407) 934-7081 (fax) 1,2,3,4,5,6,7,8,9,10,12,13

#### **Water Country USA**

176 Water Country Pkwy Williamsburg, VA 23187 (804) 229-9300 (voice) (804) 253-3399 (fax) 1,2,3,5,6,7,10,12

This directory was compiled by Michele San Filippo, an Exceptional PARENT Intern.

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Circle #156

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ERIC

### ramiliar faces

SUMMER FUN!

Suzanne Ankrom of Rifton, New York says she could have never imagined air travel with an adolescent in a wheelchair—not until last summer, when daughter Christina, 18, who has cerebral paley and communicates with a Light Taiker, was offered the chance to spent a week at an augmentative communication camp in California. Before long, plans for a west-coast family-vacation were in the works!

After Christina's week at camp, the Ankroms spent a memorable week seeing the sights in San Francisco, Yosemite and Lake Tahoe. On a day trip to the Muir Woods, a detour from the wheelchair-accessible paved pathways found 18-year-old Christina and dad Mike inside an ancient giant redwood tree. "Now," says Mom, "I wouldn't hesitate to fly off to another distant adventure!"



Michelle Coe, 5, of Aurora,
Colorado, enjoyed meeting Robin
Hood and Maid Marian during a
1993 trip to Disney World. Michelle
was born with a defect of the first
cervical vertebra which resulted in
quadriplegia; she has been ventilator-dependent since the age of five
months. Her morn, Ellen, says she
has always been determined to give
Michelle the same opportunities and



experiences as other children of the same age.

A few near-catastrophes occurred during their Florida trip, in a sudden, drenching downpour in the Magic Kingdom, Michelie's power wheelchair and ventilator both stopped working. Difficulties in obtaining a rental ventilator made Ellen vow to bring two along on every future trip—"As with anything we do in life, we come away with new experiences and better ways to plan for the next time. Most importantly, however, all Michelie talks about are the good times and good memories from this vacation. And isn't that what it's all about, anyway?"

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!



Alexandra Maniscalco, 4, and father Thomas catch some rays during a seaside vacation in Cape May, New Jersey. Alexandra was born with a translocation of chro-

mocomes seven and nine. She is fed through a g-tube and requires oxygen while sleeping. Parents Thomas and Louise enjoyed visits to Cape May before Alexandra was born, but find it to be the perfect vacation for their daughter as well. "She gets to lay down on the beach and we put her feet in the ocean," says her dad. "It's a different experience for her." When not on vacation, the Maniscalco family resides in Yorktown Heights, New York.

Five-year-old Adam Dreisbach waits for a wave with dad Tim during a 1991 family vacation in Myrtle Beach, South Carolina. Adam's morn, Suzan, believes she has found the key to a successful family vacation with a child who has a disability—"You shouldn't stop doing things as a family. You just need to find eut what the child likes to do and plan



around that. We know Adam doesn't like amusement park rides, but he enjoys any activity involving water; that helps us make our vacation plans, and we have a great time!" The Dreisbachs—Tim, Suzan, Adam, now 8, and Brian, 14—live in Northempton, Pennsylvania. Adam has a seizure disorder.



The Totey family, including eight-year-old twins Allison and Brian, enjoyed visits to several California theme parks during a 1994 family vacation. Mom Janice had high praise for the

necessibility of Universal Studios in Hollywood, noting that the tour tram even had a hydraulic lift for boarding heavy power wheelchairs. A high point of the tour came when the twins met Harry, star of the movie Harry and the Hendersons. The Toteys live in Renton, Washington—the heart of "bigfoot country"—where Harry and his relatives are local legands.



• EXCEPTIONAL PARENT / APRIL 1995

# **MOVE International**

GIVING CHILDREN INDEPENDENT MOBILITY AND CHOICES

OVE International is about people who care. About dedicated individuals who took a hard look at their past work and had the courage to call it a failure. About people who are challenged by immobility, and about the people who care about them. People like Linda Bidabe.

#### ADMITTING FAILURE

MOVE—Mobility Opportunities Via Education—began with children who had severe mental and physical disabilities and attended the Blair Learning Center in Bakersfield, California. In the early 1980s, the staff of the center decided to take a cold,

hard look at the outcomes of their efforts with these children.

The results of this evaluation were depressing: Sixty-three percent of the students who had profound disabilities and were nonambulatory were func-

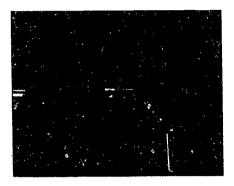
tioning *below* the six-month level of motor skill development. These children had entered the educational system at three years of age. However, by the time they left school at age 22, many seemed to have *fewer* skills than when they had entered. Babies were growing into young adults with painful deformities and bleak futures. Many students had such poor head and trunk control that they could not sit unsupported; most could not feed themselves or use the toilet.

Linda Bidabe, an educator working for the Kern County Superintendent of Schools Office (which operates the Blair Center) realized that one reason for this apparent regression in skills was that the children spent most of their time reclining in bean bag chairs or strapped into wheelchairs. As they grew older and heavier, gravity became the enemy. With increasing size and weight, the children became less able to bear weight on their legs, pull up to a sitting position or take reciprocal steps. With lack of use, their limbs became less flexible and less amenable to manipulation or therapy. Over time, the children's educational program turned into custodial care; teachers and therapists had to spend so much time caring for the children's basic needs—positioning, feeding and toileting—that there was little time left to help the children learn new skills.

#### PILOT PROGRAM

A dynamic and gifted teacher, Linda refused to accept this situation as the inevitable result of severe disabilities. In the summer of 1986, Linda's office created a mobility pilot pro-

gram to focus on just three skills—sitting, standing and walking. The students involved in the program were between the ages of six and 16; all had multiple disabilities. None of the children had ever walked. Only one had any speech. The program

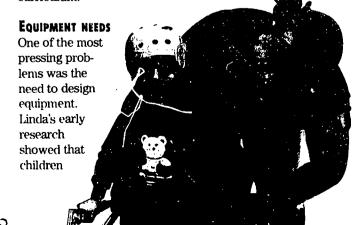


involved integrating every aspect of the educational curriculum into a physical activity that could help teach specific motor skills. For example, during speech therapy, the children were placed in an upright stander instead of a wheelchair. During art, students would sit in chairs that had been slightly modified to provide support and prevent falls but that would encourage their back and stomach muscles to work throughout the duration of the activity.

The results of the pilot program were astounding. The teachers worked with individual children throughout the day on specific motor skills, such as sitting or standing. Within a matter of days, an individual child would progress from tolerating this activity for a few seconds, to sitting and standing for an hour or more.

Not only were the children mastering the motor skills that had been the original objectives of the program, they were also becoming more alert and interactive—laughing and making attempts to communicate with their teachers and with each other. Giving a child a means of independent mobility—and the opportunity to make choices—became the foundation for the development of additional skills.

Teachers were amazed. Parents were thrilled. It was obvious the program needed to be defined and expanded. Through a Rotary International fellowship, Linda spent a year in Australia replicating the early successes of the program and doing research to write the MOVE curriculum.



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#### SPECIAL ADVERTISING SUPPLEMENT

### AMBER STEENBOCK

ver store I can remember; I have wented to get around and go places. This Landstate is reasonable to do with moving being a big part of my childhood. I was born to Jupen. About three months later, my parents and I moved to

Even as a very young child, I seldom allowed my physical disability (quadriplegic speaks; carebral peloy) to interfere with my perpetual goal of being on the move.

Also mastering the art of rolling: I found this to be a relatively fast and efficient

mede of travel for my little body.

After kindergerten, we moved to Kentucky, There, I got my first motorized wheelchair. The wheelcheir ektin't go very fast, but I enjoyed my new freedom, and thought I was not stuff. So did my new neighborhood friends. Together, we discovered a great

Tree way to have full. A jump groups was fied to my chek Shandle, and six or eight roller skalers were given a "highapped" low.

A couple of times; I even ran away from home. I packed my little toy suitcase with my favorite triings and drove angrily down the sidewalk—but I always changed my mind by the time I turned the first come:

After eighth grade, we moved to our farm in Oregon and put down some roots.
My sisters and I attend Marshfield High School, where I am a senior.

When my physical therapist introduced me to the MOVE program at the beginning of the last school year, I



Amber Steenbock enjoys the view from her family's deck with buddies Scooter (on lap) and Rebel.

was interested. She told me that this was no ordinary program. Rather than the therapists telling me what to do, I would be in control of the pace and order in which I progressed. That sounded very cool. So, we went to work.

I wasn't very impressed in the beginning. Learning to balance in a regular chair was hard work. It took a long time and it wasn't much fun. But after I mastered that skill, things started moving faster. Next, I worked on "prompted" standing for three minutes, and then prompted walking, supported from the front or the rear.

in December, I met a brilliant, fun and incredibly understanding woman named Linda Bidabe, the creator of MOVE. Linda brought me a Rifton Gait Trainer. I stood there for a minute, feeling an awesome sense of control. This was going to be the first time I would walk under my own power. I took off across that cafeteria, and I've never looked back.

The Gait Trainer is a walker with adjustable, removable prompts. Aiready, my "training wheels" have been removed; next I'il lose the seat.

MOVE has opened doors for me. Transfers are easier. I eat lunch in a regular chair. I walk the halls after school and chat with friends. I am able to "dance." Almost every day, I gain confidence, and am surprised by new or better abilities.

-Amber M. Steenbock

Amber M. Steenbock, 17, lives with her sisters Erin, 16, and Audrey, 14, and parents, Mark and Deborah, on a family farm in Coos Bay, Oregon. Amber loves reading, writing and using her computer. She also enjoys working with small children; one of her goals is to become an elementary or pre-school teacher.

with profound disabilities often required more than 2,000 practice sessions to master a single new motor skill. Public education simply did not have the resources to hire the additional personnel needed to hold children in place while they practiced these skills. The equipment that was needed to support the MOVE curriculum did not exist.

In the beginning, Linda and the staff of the Blair Center created their own equipment using little more than old bicycle parts and imagination. Then, in 1990, Linda asked the Hutterian Brethren, members of a Christian community who operate Rifton Equipment, if they would like to work with the Kern County Superintendent of Schools to meet the unique needs of this program. The equipment had to be versatile enough to serve a variety of students with varying levels of proficiency, yet sturdy enough to be passed down from class to class as children progressed through the program. The equipment needed to support children with the most severe disabilities, yet that support had to be progressively removable as students gained strength and skills.

As a result of this collaboration, Rifton designed and created several key pieces of equipment—the Mobile Prone Stander, the Universal Chair Frame and the Gait Trainer. Each piece of equipment uses a series of "prompts"—belts or straps—that provide support to different parts of the body and can be gradually removed as a child develops skill and confidence.

#### THE CURRICULUM IN ACTION

MOVE takes a practical, common-sense approach to teaching children to sit, stand and walk.

For years, many doctors, therapists and teachers have believed that in order to walk, children must first learn to push up and crawl. The natural inclination of adults is to begin teaching where children start failing. Unfortunately, this approach did not work well for children with the most severe disabilities. As children worked on skills like crawling or rolling, they grew into adults who were still working on the same skills.

MOVE turned that model on its head. Instead of using a "bottom-up" model based on typical infant development, Linda began by doing a task analysis of the skills the children would need to lead functional, dignified lives—skills like bathing independently, feeding themselves and using the bathroom.

#### **MARKUS SMITH** Working toward a dream

'arkus' physical therapist. Darron Veh. called me in LOctober of 1994. He wanted to "try something different" with my son. Markus is 10 years old and has cerebral. palsy. We had "tried" many different things to improve his motor abilities, but Markus had made little progress in the tast several years. Markus could stand in a prone stander. but hated it. He could wheel himself slowly and erratically in his wheelchair, but required assistance to travel any distance. His poor vision made motorized mobility risky. What type of experiment were we going to subject Markus to this time?

Darron introduced us to MOVE and the Gait Trainer and Mobile Stander. Markus loved the stander and was immediately able to wheel himself around in an upright position. Markus then tried the Gait Trainer. He struggled, but couldn't quite get it moving. As a team, we discussed which piece of equipment Markus should work with. We decided to work with the Gait Trainer because it would provide more room for improvement.

Markus initially required every prompt on the Gait Trainer and assistance to make it move. These struggles in the school hallways produced benefits far beyond the physical. Markus' schoolmates stopped to encourage him. A class of eighth graders gave him a spontaneous ovation. Teachers and students encouraged Markus and applauded his



every little success. His self confidence began to grow.

A year ago. Markus told a doctor, "My greatest hope is to walk someday." He was now taking his first steps toward this dream.

After just four months, Markus is able to walk 30 to 40 minutes a day in his Gait Trainer, for distances of up to a half a mile. He now requires only the forearm supports and one leg prompt. He still has trouble controlling his direction, but the power is all his.

Markus has moved out of a wheelchair desk, and into a "regular" desk. He said. "I love having a desk like the other

kids. I can get my own books and pencils and that other stuff." Even Markus' wheeled mobility has improved. His wheelchair speed has tripled, and he now wheels himself around the school completely independently.

My husband, Michael, has always felt Markus could walk if we could find the right equipment to give him the support he needed. We finally found the equipment and the approach. We look forward, with anticipation, to seeing what Markus can accomplish next.

-Gilda Smith, with Darron D. Veh

Markus Smith is a third grade student at Nickerson Elementary School in Nickerson, Kansas.

Darron D. Veh. P. T., is a physical therapist with Reno County Education Cooperative, which provides special education services to Nickerson Elementary School students.

Instead of starting at the point where a child begins to fail, the MOVE curriculum starts at the point where he or she begins to succeed. MOVE starts with real life skills.

Upon entering MOVE, a child is assessed starting at the highest skill level and moving down to the first level at which he or she demonstrates proficiency. If, with support, a child can bear weight and move his or her legs reciprocally, why work on the skill of crawling? With continued practice and the application of MOVE principles, many can learn independent movement.

#### MOVE GOES INTERNATIONAL

The success of MOVE has been phenomenal. The curriculum has been translated into seven languages, and training workshops are conducted throughout the United States and Europe. Today, MOVE International, a not-for-profit organization, is supplying information about the MOVE program to people in all parts of the world.

For more information, contact: MOVE International, City Center, 1300 17th St., Bakersfield, CA 93301; (805) 636-4560 (voice).

#### SIMON THORPE

Hard work leads to greater independence

n 1993, 11-year-old Simon Thorpe received a McDonald's Child Of Achlevement Award for sitting on a standard chair at a table and feeding himself. For Simon, these "simple" tasks represented a major achievement.

Simon was born with profound learning and physical disabilities - including difficulties in moving and controlling all four limbs. His family was determined that Simon should live as full and active a life as possible. Together, the family worked to encourage Simon to move.

In 1984, Simon began to receive home-based physi-

340

cal therapy. At five, he began to attend Gorse Bank School in Chadderon, England, a special school for children with learning difficulties, where therapists, teachers and parents work closely together.

By 1992, Simon was able to sit in fully supported seating and could tolerate being placed upright in a standing frame. However, he was unable to feed himself, sit on a standard classroom chair or walk.

In June 1992, with the backing of school officials, the physical therapy department introduced MOVE. Simon's participation required teamwork from parents, teachers and therapists; but above all, it required hard work from Simon.

After one year, Simon was able to sit on a standard chair without support and feed himself. Following major surgery to his legs, Simon is now learning to walk.

-P. Norbury

Mrs. P. Norbury, M.C.S.P., S.R.P., is supervising physiotherapist of the Learning Difficulty Services department at Gorse Bank School in Chadderton, England.



Simon Thorpe received a 1993

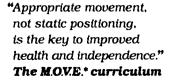
Award from British breaststroke

television star Trudi Goodwin.

McDonald's Child of Achievement

champion Nick Gillingham and British







Walking with his father is now a daily joy for Duane Bazeley. Thanks to his parents, teachers, M.O.V.E.* and Rifton Equipment, Duane is making real progress. The M.O.V.E.* curriculum teaches standing, walking, and functional sitting skills to children with disabilities. Working in partnership with M.O.V.E.* founder Linda Bidabe, Rifton has developed a complete line of equipment to support the M.O.V.E.* program.

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### rathers voices

# Hey, Mister! Is She Retarded?

by Steve Volkert

"Hey, mister! Is she retarded?" "What?!"

"Is she retarded? She sure acts like she's retarded."

e were on vacation—just a long weekend really. Spending some time at the Iowa Lakes. Just kicking back, relaxing, trying to regroup and recharge. Stacy and I

were in the swimming pool, splashing and playing like any other daddy and daughter. We weren't thinking or worrying about the differences our family has learned to live with over the past nine years.

Then along comes this very inquisitive, very straight-forward seven-year-old kid with a question—"Hey, mister! Is she retarded?"

My first reaction was to grab Stacy, get as far away from the pool as possible, and sit down and cry. Then I thought about really letting this kid have it—with both barrels! I could say

something like, "How dare you, you blankety-blank little twerp?" Or, maybe if I held her underwater for a few minutes, it would clear her thinking and wash out her mouth!

Then I looked around. The little girl wasn't alone; she was with three other, slightly older girls who were looking at her in disbelief. One of them even said, "You don't ask questions like that."

I looked into the eyes of the girl who had just ripped my heart out. I didn't see hatred or hurt—only the innocence

of yor'th. From somewhere deep inside me, a voice asked, "So, what are you going to do'."

To make a long story short, we stood in the pool and talked. Talked about what it means to be different. Talked about sign language. Talked about how everybody is special, how all of us have something we have problems with and about working together to help each other. In the end, Stacy had made some new friends. For the next two days, they were inseparable. Then we all went our separate ways.

That was three years ago. Last summer, we

were spending another couple of days at the lakes when I heard someone say, "Hey, Stacy! Remember me?"

You guessed it-same kid! Only



Dad holds Stacy moments before she had her ears pierced—part of her thirteenth birthday celebration.

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (205) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and menturing programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.



Ptay ball The entire Volkert family—(from left)
Chad, Steve, Stacy, Mary and Steve—is
involved with Challenger League baseball.
Parents Steve and Mary coach Stacy's team;
brothers Chad and Jeff help individual players
during practice and games.

this time she had different questions—"What grade are you in? What school do you go to? Are you having fun this summer?"

This time, she was talking to Stacy, not about Stacy! Then, this little girl, the same one who had torn my heart



Dad keeps a watchful eye as Stacy, then 4, wades in a river during a family vacation in Minnesota.

out not so long ago, reached out and touched my heart again. It was impossible to hide the tears when I heard her say, "You know what, Stacy? I've been telling all my friends at home about you. And you know what else? I think I'd like to be a special ed. teacher someday!" **EP** 

Steve Volkert lives and works on a family farm in northwest Iowa. In addition to farming, he works part-time as a parent coordinator for the Parent-Educator Connection Program at the area education agency where his wife, Mary, works as an inclusion associate in a first-grade classroom. Steve and Mary have three children—Chad, 18; Jeff, 15; and Slacy, now 14.



# **Help Wanted**

Summer and part-time jobs provide valuable experiences.

by Doris M. Willoughby

id you, as a child or teenager, gain valuable experience through a summer or part-time job? Your son or daughter with a disability can do the same.

I see four stages through which a youngster passes in moving toward adult job responsibility. Although all youngsters move through this progression in one way or another, it may be helpful to analyze this more carefully with a young person who has a disability. The second stage, especially, is often given little thought; but careful attention to experiences at this level can aid greatly in proceeding to the third and fourth levels of responsibility. (See, for example, "Adventures in Babysitting" below.)

1. Doing chores in the home, gradually taking on more responsibility. A child may be given responsibility for picking up toys, howsehold cleaning, washing dishes, taking out the trash, caring for pets or helping to care for younger siblings.

2. Working at a job outside the home while an adult is present for guidance as needed. Examples may include working as a mother's helper, entertaining children while the parent is present but busy; assisting with jobs at a local business; doing house-cleaning or other chores for a neighbor, under close direction; or learning work skills under the supervision of a teacher or job coach.

3. Working independently at a job with some responsibility. The youngster may shovel snow, deliver newspapers, wash dishes in a restaurant, baby-sit for one or two children (with an adult on call in case of serious problems) or do office work.

4. Holding a job with greater responsibilities.

As a youngster takes on more and more responsibility, he or she can also earn more money. Even at the first level, it is very helpful if children can receive payment for certain jobs; this teaches that successful work brings the agreed-upon wages, while failure results in no wages. I am not suggesting that youngsters be paid for all charges they also need to learn to

youngsters be paid for all chores; they also need to learn to carry their own weight as family members. But it is instructive to pay the child a small wage for certain chores—perhaps those that are optional or more difficult.

The volunteer option

While recognizing the importance of earning money, volunteer work can also provide valuable benefits. Sometimes, volunteer work can turn into a paying job with the same organization or group. Even when volunteer work does not lead directly to actual employment, it can offer excellent experience.

Doris Willoughby has worked as a teacher of both blind and sighted children. She is the author of two books on education for children who are blind. She lives with her husband, Curtis, in Arvada, Colorado. Curtis was one of the first blind individuals to be educated and employed as an engineer. Doris is sighted.

This article was adapted from a longer article, "Part-Time and Summer Jobs," which appeared in Future Reflections (Spring/Summer 1994), the quarterly publication of the National Organization of Parents of Blind Children (NOPBC). NOPBC provides information and support to families of children who are blind or visually impaired. Family membership is \$8 per year, and includes a subscription to Future Reflections. For more information, contact NOPBC, 1800 Johnson St., Baltimore, MD 21230; (410) 659-9314 (Voice).

#### ADVENTURES IN DADISH TING

# A young woman's first job benefits two families

BY BEVERLY K. SHERMAN

A fter six years of being home with my children, I returned to work in 1991. My son, Benjamin, was six and a half, and my daughter, Anna, was two and a half. Making arrangements for Anna was easy; she began attending a daycare center. But what would I do with Ben? Ben has severe mental retardation. He is non-verbal and nonambulatory, and has a seizure disorder (under



Babysitter Dawn Sander, 17, reads a book with Ben Sherman, 10.

control). At the time, he still wore diapers.

Because of his sensory integration problems, the noise and commotion of a daycare center would make Ben miserable. I also knew that the teacher-student ratio would not be adequate. My husband and I also decided against a family daycare home because Ben is very difficult in other people's homes. He is very unhappy unless he is watching his videotapes. He also would not be interested in playing with other children. We needed a sitter in our home.

Ben attends Kirk School, which serves students with mental retardation and multiple disabilities in the suburban Chicago area. My husband, Alan, a computer consultant, arranged his schedule to be home in the morning so he could take Anna to daycare and put Ben on the school bus. For after-school care, we advertised at the local high school, and found a student to come to our home until I returned from work. Over the next year and a half, we used two other high school students. When our last sitter graduated, we found ourselves in a bind.



Alan and Beverly Sherman, with children, Ben, 10, and Anna, 6.

While fretting over where we would find a sitter, I began thinking about what the job really entailed. The sitter needed to get into my house, take Ben off the bus, put him on the toilet, and turn on the television and videotapes. Ben never varies from his routine. It was not a "difficult" job. I just needed a reliable person who could phone my husband or me in case of an emergency.

Stunned, but thrilled

I decided to ask Glady Sander, one of our neighbors, if she thought her daughter, Dawn, might want to babysit for us. Dawn attends the special education program at our local high school. She had always enjoyed coming over and playing with my kids.

Glady was stunned at my request, but phoned four days later to say she and her husband would be thrilled for Dawn to have her first job. However, they were worried that this might be too big a step for her. They were concerned about my son's needs and the responsibility Dawn would be assuming.

They eventually decided to let Dawn work for us, feeling

they would never know Dawn's full potential unless she was given the opportunity to try. Glady is home in the afternoons and would be able to stay with Dawn for the first few months while Dawn learned the routine. Glady would also be available whenever a problem came up.

When we asked Dawn what she thought about working for us, she was so excited. She immediately said, "When I go to their house, I can bring in their mail!" We all felt this comment was a good sign because it showed her initiative.

The next Saturday, Dawn and Glady came to our home, armed with a clipboard and a list of questions. I showed Dawn how to unhook Ben's bus harness, how to put him on the toilet and how to work the VCR. We talked about what to do if Ben soils his pants, what to do if he is unhap-



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Circle # 42

#### "Hi, honey, I'm home!"

ou would have thought we had won the million-dollar sweepstakes when Bev Sherman asked Dawn to babysit for her. It sounded too good to be true.

But we received a prize more valuable than money. Our daughter was given the opportunity to be gainfully employed. Dawn was to receive much more than a paycheck. The value of this iob cannot be calculated in monetary sums.

It has been two years since Dawn began caring for Ben. At the conclusion of her work day, Dawn arrives home with a smile and a spring in her step. As I open the door to welcome our "working girl" home, she often cheerily exclaims, "Hi, honey, I'm home!"

"Pay day" is Dawn's favorite day. She marches proudly into the bank with her paycheck. Some of the bank employees who have gotten to know Dawn have even attended the Special Olympics to cheer Dawn on.

Should you ever have the privilege of meeting Dawn, her job is one of the first things she would tell you about. She is so proud of her caregiver responsibilities and seems to have a real gift for working with children.

As part of a recent English assignment at school, Dawn was asked, "If you could be any person in the world or could have anything you wanted, what would it be?"

Dawn's answer: "To be a teacher and teach kids."

---Glady Sander

Glady Sander lives in suburban Chicago with her husband, Dick, and children, Todd, 22, and Dawn, 17.

py and what he likes to eat. We also agreed that Dawn would not answer the doorbell or the telephone.

This first meeting made me realize how complicated this "easy" job really was. I was afraid Dawn felt overwhelmed by the many Jetails we had discussed; still, I felt that with enough

time, Dawn would be able to handle the job. It was comforting to know that Glady would be there every day until Dawn understood the routine.

After about a month, Glady felt comfortable merely being in my house while Dawn worked; that is, Glady would be in my living room while Dawn met the bus and took care of Ben in the family room. After a few weeks, Dawn felt ready to do it all by herself. Dawn would call her mom when she arrived at my house, and again after bringing Ben in from the bus. Although Glady would sometimes come by to help Dawn with her homework, Dawn was the one looking after Ben.

#### The unexpected

The hardest part for Dawn was when something out of the ordinary happened.

For example, one time Ben knocked over a picture frame and cut his finger on the glass. Another time a plumber showed up early for an appointment, and repeatedly rang the doorbell. Dawn called her mother and Glady ran over to see who was at the door. These types of situations presented no challenge for

# Community Living Opportunities

For more than 65 years, Martha Lloyd Community Services has provided superior quality day and residential programs for adults with mental retardation. Located in the scenic rural village of Troy, Pennsylvania, Martha Lloyd has a unique relationship with its neighbors. Residents are valued members of the community and make full use of its resources.

There are five programs for women (from semi-independent to highly structured) including one specifically designed for mature women. A new community-based program for men is now available.

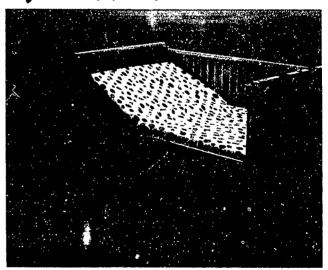
- Life skills and vocational training.
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Beverly Sherman lives in suburban Chicago with her husband, Alan, and children, Ben, 10, and Anna, 6.

#### NV MI ANTHONO BENEFIT OF THE

by Earl Schive

ast summer, I got a newspaper route. I deliver newspapers every morning by 7 a.m. Every week, I collect money from my customers. I pay my bill at the newspaper office on Fridays, and then I keep the money that is left.

On my first collection day, I felt very nervous. I wondered how I could communicate with my customers. What would they think about me? Would they dislike me or think I am stupid because I am deaf?

I went to the first customer's house and knocked on the door. The woman opened the door and I showed her the money collection cards and pointed to show how much money she owed me. The woman realized I was deaf. She nodded her head and gave me the money with a smile. I still felt nervous but after a few houses, I realized it would not be that hard, so I relaxed.

In November, there was a contest to get new customers. I wondered how I could win one of the prizes. Hearing newspaper carriers could talk to people and ask them if they wanted to subscribe. I couldn't talk so what could I do?

Then I had an idea. My idea was to make a big poster that said, "I deliver the *Boston Globe* in this neighborhood," and explained the full service. I stood near the store where people buy newspapers each Sunday. Every time I noticed people carrying the *Boston Globe* from the store, I approached them and showed them the poster. The first time I tried this, I got two new customers. I did this every Sunday for five weeks. As a result, I got more new customers than any other kid in my town. I won many contest prizes; I got a watch, a \$25 gift certificate and cash.



Earl Schive kept his newspaper route for nearly four years.

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#### **Help Wanted**

As I continued delivering newspapers, some customers became my friends. They tried to find ways to communicate with me. For example, Mrs. O'Brien, an elderly woman on my route, started writing notes to me. She left them in her door with her newspaper money. I wrote some notes back to her. Then she started to leave little gifts for me. She treated me almost like a grandson.

Other customers on my route have also become my friends. We find ways to communicate. I have taught some customers some sign language. With others, I write notes or try to understand their lips. We discuss sports and sometimes they ask me questions about myself.

I have learned a lot from having this newspaper route. I have learned to be responsible; I have learned that I can find ways to communicate with and become friends with hearing people; I have learned that I can do as good a job as hearing kids.

Earl Schive, now 20, was born profoundly deaf and has additional mild physical and learning disabilities. He is the adopted son of EXCEPTIONAL PARENT associate editor Kim Schive.

Earl wrote this essay when he was 13 years old. It won first prize in the "Deafness" category of the 1988 Creative Contest sponsored by the National Association of the Deaf and WORLD AROUND YOU, a magazine for deaf and hard of hearing teenagers. (For information about WORLD AROUND YOU, contact

Gallaudet University, Pre-College Programs, KDES PAS 6, 800 Florida Ave. NE, Washington, DC 20002-3695, 202/651-5340, V/TTY. Subscriptions cost \$7 per academic year for five bimonthly issues; order line: 800/526-9105, V/TTY.)

#### WORKING ON THE CONSTRUCTION CREW

by Charles Cheadle

L ast summer I worked for Wilhelm Commercial Builders, a construction company in my area.

We spent most of the summer rebuilding a basement in a renovated factory building. The basement floor was above a large underground chamber that had been sealed off years ago. We needed to fill in the lower chamber with concrete to prevent water damage from below. Under the supervision of our foreman, we removed flooring and hauled it in huge pieces to a nearby dumpster. The work was tedious, slow and grueling.

The floor was roughly six inches thick. On the bottom was three and a half inches of spline-jointed Georgia pine covered with one-inch tongue-and-grooved maple. On top of those two layers were two more layers of three-quarter-inch plywood covered with rubber tiling.

Breaking up the floor was no cakewalk! We took it up in sec-

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347

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On the job: Charles Cheadle helps other members of his construction crew remove the basement floor of an old factory building.

tions. First, we removed the linoleum-plywood layer in four-foot squares. Next, we removed the maple, which was very securely nailed in place. To take up these two layers, we used wrecking bars which we jammed under the nails to pry them free.

My blindness caused me trouble only when it was time

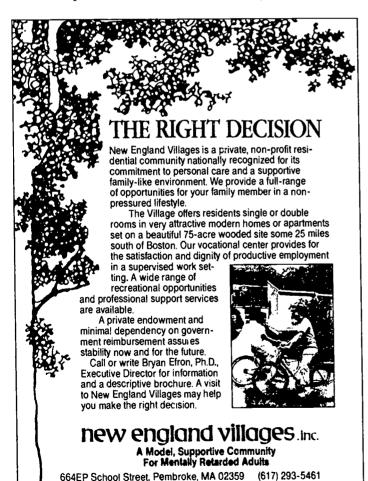
to pick up the wood. I had to be careful not to stab myself. I used a simple technique—"Don't go grabbing wood in a hurry!" I also found that by initially reaching out a few inches above the wood and then carefully picking it up, I could avoid the larger splinters and nails.

Our next step was to remove the pine timbers. When the timbers were cut free we had to carry them out and stack them in the dumpster too. This was the last layer of the floor; when it was removed, our place to stand went with it. Now the surface was full of holes with a sevenfoot drop-off. This intimidated me at first, but because the work had to be done, and I liked having a job, I had only one option—I just made sure I was constantly aware of where the holes were and where I was. I figured as long as I wasn't on top of where a hole was, I would be OK. This proved to be a good strategy, and I didn't encounter any hostile or malicious holes subsequently.

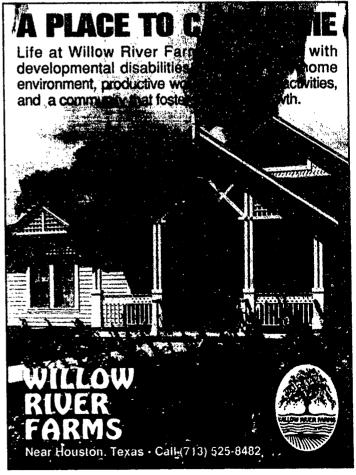
The few problems I had did not hinder my productivity in any way. Yes, they did seem difficult at first, but taking an open-minded approach helped me come up with solutions. Careful thought and some planning will go a long way in ensuring a safe and productive work environment. **EP** 

Charles Cheadle, 17, has been blind from birth. He lives in Baltimore, Maryland with his adoptive parents, John and Barbara. A junior honors student at Catonsville High School, Charles is a member of the cross-country team and active in Boy Scouts and a local National Federation of the Blind chapter.

Charles' father helped Charles and his older brother get summer jobs with Wilhelm. Though the presence of his older brother was initially reassuring to Charles' supervisors, it was not integral to his success. He has been offered another job with Wilhelm this year—with or without his brother.



Circle #21



Circle #91

## RESEARCH



# **Preventing School Failure**

Students with learning disabilities have special instructional needs

by Louisa Moats

n the last 20 years, our understanding of many specific learning disabilities has grown significantly. Among the various learning disabilities, disorders of language comprehension, language expression, reading and writing are the most common. Up to 80 percent of the children we categorize as having learning disabilities, in fact, have disorders of language. These language-based disorders include reading and writing disabilities.

Through research we know that listening, speaking, reading and writing are closely related language skills. For example, preschool children with disorders of oral language-meaning listening and speaking-usually develop difficulties learning to read and write. Conversely, most children who encounter reading failure demonstrate a basic deficit in speech perception and speech sound processing.

These children have trouble detecting the speech sounds in words and associating them with letter patterns. For example, younger children with reading disability usually can tell that spoken words like "moats" and "most" are different, but cannot identify which sounds are different or how many sounds there are in each word. They may also have difficulty with rhyming Effective programs for reducing reading failure involve individual or very small group instruction by a well-trained teacher.

activities, word games (such as pig Latin) and activities requiring them to count or change the sounds in words. They may have unusual trouble learning the differences between words such as "goal" and "gold." I knew one child who sat through an entire lesson on the Gold Rush and thought that the teacher was talking about "goals," like soccer goals.

Children with these language disabilities have difficulty discriminating between words such as "boost" and "boast," or "unanimous" and "anonymous." Such children have a weak sense of word structure which undermines their ability to learn the code of written English. As time goes on, this problem, in turn, undermines their vocabulary, reading comprehension,

spelling, written expression and their motivation for language-based learning. Obviously, they are at high risk for school failure.

Do we know how to teach these students? Yes; educational researchers have agreed on the essential components of effective teaching. Model schools and programs with low rates of failure do exist. Do we practice what we know? No; not on a nationwide scale that would make a difference. Clearly, several educational policies and practices must be altered to clear the way for better implementation of good teaching practices for students with learning disabilities.

#### Early intervention essential

First, reading failure can be prevented for all but a very small percentage of children. Intervention, however, must begin early in kindergarten and first grade. The longer intervention is delayed, the more likely it is that a child's failure will become entrenched. Programs which have been proved effective in reducing reading failure involve individual or very small group instruction by a well-trained teacher. Examples of such programs include Project Read Out of Minnesota, Success for All in Baltimore and Philadelphia, Reading Recovery

349

in New Zealand and Ohio, the Winston/Salem Project in North Carolina, Benita Blachman's projects in New York City and Syracuse, and many others.

Effective prevention of reading failure includes reading and writing practice with a wide variety of worthwhile material. But, most importantly, effective prevention includes the direct teaching of speech sound awareness, alphabet knowledge, the links between sounds and symbols and fluent decoding of print (the ability to go from looking at printed words on a page to comprehension of meaning). In the case of reading disability, the nature of the problem suggests the nature of the cure—those children who are not sensitive to words can learn when the word structure is taught to them explicitly. Though not part of the standard reading curriculum, this type of instruction should be available in every school for those who need it.

#### A full continuum of services

Secondly, the policy known as "full inclusion" should be replaced by the original provision of the Individuals with Disabilities Education Act (IDEA)—a continuum of services and placement options for students with learning disabilities. In the schools I visit, full inclusion has come to mean that students with learning disabilities receive little or no appropriate instruction in mainstream classes. Those who learn differently are not being taught differently.

Typically, teaching assistants are placed in regular classes to adapt curriculum and walk children through inappropriate assignments. Educators often have neither the administrative support nor the time to instruct children in the basic skills they lack using research-supported methods that address their language, attention and

#### **Participation in Research Studies**

Researchers are currently looking for participants to take part in the following research studies. The information has been reprinted with permission from *Orphan Disease Update* (Fall 1994), the newsletter of the National Organization for Rare Disorders (NORD), 100 Rte. 37, PO Box 8923, New Fairfield, CT 06812, (800) 999-6673 (voice), (203) 746-6481 (TTY), (203) 746-6481 (fax).

#### **BRANCHIO-OTO-RENAL SYNDROME**

Research aimed at identifying the gene on chromosome 8 that causes Branchio-Oto-Renal syndrome is being conducted by Dr. W.J. Kimberling and Dr. S. Kumar at Boys Town National Research Hospital (BTNRH). Volunteers will be asked for a family history, medical records and a blood sample. Researchers will pay for or reimburse expenses associated with these requests.

• Contact Tom Fowler, BTNRH, BOR Project, 555 N. 30th St., Omaha, NE 68131, (800) 835-1468.

memory deficits. Students with learning disabilities may be able to pass courses because the teacher changes their assignments, or someone reads to them, or someone writes for them, but they are *not* learning how to read, write, calculate, solve problems and study.

Mainstream teachers usually have not been trained to teach language in a structured way and do not have the energy, time, commitment or expertise to be all things to all students. Some students with learning disabilities can be mainstreamed with curriculum adaptations, but many need small groups away from the mainstream, many need tutorials and a few need self-contained day programs and residential placements.

It is not *where* instruction takes place, but the *quality* and *focus* of that instruction that ultimately determine the success of students with learning disabilities.

This article was adapted from remarks presented by Louisa Moats, Ph.D. at the Summit on Learning Disabilities. Louisa Moats is the director of teacher training and clinical services at the Greenwood Institute in Putney, Vermont. The Summit, sponsored by the National Center for Learning Disabilities, was held in Washington, DC, Sept. 20–21, 1994.

LEARNING DISABILITIES: A NATIONAL RESPONSIBILITY, a report from the Summit, is a summary of recommendations for improving the lives of individuals with learning disabilities. This 24-page booklet costs \$4 (including postage). It is available from the National Center for Learning Disabilities (NCLD), 381 Park Ave. South, Ste. 1420, New York, NY 10016; (212) 545-7510 (voice), (212) 545-9665 (fax). NCLD has other available publications, and can provide information and referrals to parents of children with learning disabilities. Contact them for more information.

#### **POLYMYOSITIS AND DERMATOMYOSITIS**

Researchers are seeking volunteers with polymyositis or dermatomyositis who have blood relatives with any type of myositis. This investigation is looking at genetic factors that might be responsible for certain connective tissue diseases. Volunteers will fill out a questionnaire and donate a blood sample.

 Contact Dr. F.W. Miller or Dr. Lisa G. Rider, Molecular Immunology Lab CBER, FDA, National Institutes of Health, Bldg. 29, Rm. 507, HFM-521, 8800 Rockville Pike, Bethesda, MD 20892, (301) 496-6913.

#### **DIABETES INSIPIDUS**

Dr. Robert S. Wildin is studying the genetic causes of congenital nephrogenic diabetes insipidus. He has identified 15 different genetic mutations in the renal vasopressin receptor in different families. He is interested in collecting more blood samples from families he has not yet studied.

 Contact Dr. Robert S. Wildin, Dept. of Pediatric Genetics, UTMB, 301 University Blvd., Galveston, TX 77555-0359, (409) 772-3466.



ما الأرا

# **IEP Strategies**

Getting what your child needs from IEP meetings and annual reviews

by Barbara Ebenstein

ow will we educate Risa? I worried about how I would communicate my daughter's special needs to our school district and how the district would respond. How could they possibly understand this beautiful child who loves without words?

Risa entered a special education nursery school class while I was a law student. My professors were understanding of my unorthodox class schedule and sudden absences. Risa experienced one educational crisis after another until I developed an approach to special education that permitted me to obtain the services she required.

I now work as an attorney representing parents in special education matters. I also conduct parent workshops. I never come away from one of these sessions without having learned something useful. The strategies presented here are based not only on my own legal knowledge and experiences, but also on the collected experiences of many parents.

#### **Ten Strategies**

1. Keep "business" records. Treat your relationship with the school district as a business relationship. All communication should be in writing, and you should keep a copy of every document you submit. Keep brief notes of important telephone conversations. Keep a written record of all verbal agreements, and give a copy to the school district.

Hand-deliver important documents directly, or use certified mail and keep the return receipt.

Keep a diary noting the dates you submit documents. Some regulations require that the district comply with time requirements. For example, they may have 30 days to respond to a written request. If so, you need to know the date you made that request. Legally

speaking, if it is not in writing, it never happened.

2. Document all of your child's unaddressed needs. A parent's insistence that a child requires a specific service is never sufficient. Every unaddressed need should be described, in writing, by a professional who knows your child or has evaluated him or her for this purpose.

Letters from your child's pediatrician, therapist or other professionals can be brief, but should include a description of the child's special need(s), its educational impact and a "prescription" for needed services.

3. Review your child's classification. Many states have lists of conditions that permit eligibility for special education services. These are educational classifications, not medical terms. For example, in New York State a child with a medical diagnosis of attention deficit disorder (ADD) may have an educational classification of "other health impaired" or "learning disabled."

Ideally, special education services should be provided on the basis of a child's individual needs. Unfortunately, some school districts provide children with services according to their classification.

If you are dissatisfied with the services your child receives or his class placement, begin by reviewing his or her classification. Is it the most appropriate classification? Would denied services be available if the child's classification were changed? If so, have your child evaluated by an appropriate expert. Your child's classification may also need to change as he or she develops new strengths and weaknesses. 4. Cooperate with the school district's reasonable evaluation process. The school district needs your consent to conduct an evaluation; however, if you refuse, they can request an impartial hearing. The hearing officer will deem the proposed evaluation reasonable, and the district may be permitted to proceed without your consent. All you will have accomplished is the destruction of your relationship with your school district. Save your energy for battles you can win.

 $5.\,Be \,sure \,the \,committee \,has \,accurate$ 

reports. If you disagree with an evaluation done by the school district, there are several steps to take. First, review the inaccurate report—what is wrong with it? Was it performed when your child was not taking his usual medication? Were inappropriate tests used? Was the evaluator

Barbara Ebenstein and daughter Risa Handelsman.





unfamiliar with your child's strengths and limitations?

Second, ask about the evaluator's position and credentials.

After receiving a devastating speech assessment on my daughter. I discovered it had been written by an inexperienced speech teacher. I obtained a more detailed report from my child's private speech therapist—a woman with a Ph.D. and many years of experience. The district followed the therapist's suggestions and agreed to remove the teacher's report from Risa's file.

If you disagree with the school district's evaluation, you are entitled to an independent evaluation at the district's expense. The district may place a reasonable cap on the cost. If the district disagrees with the necessity for another evaluation, you may need to go through an impartial hearing. But if you know an evaluation is inaccurate, it is worth fighting.

You must state your disagreement with the school district's evaluation before they use it to determine your child's placement. If you disagree later, the district will assume that your objection is to the placement rather than to the accuracy of the evaluation. This becomes a more difficult battle to win.

If all evaluations from experienced professionals are contrary to your expectations, consider whether they might be right. Is it possible that you are denying the severity of your child's problem? If not, pursue other experts at your own cost. If you obtain private reports, it is your choice whether or not to share them with the team. You may decide to share only those documents that strengthen your position. 6. Build accountability into the child's IEP. The school district has a legal obligation to make the necessary arrangements to provide related services promised on the IEP. If a related service is not provided as required, parents have a right to full due process. Request an impartial hearing in writing. Most districts will solve the problem immediately rather than face the time and expense of an impartial hear-



Dr. John Handelsman and daughters (from left) Leanne, Risa and Sarah.

ing they will probably lose.

The follow-up of specific educational objectives is more difficult. For example, a child who is included in a regular class may have a classroom teacher, a resource room teacher and a psychologist. Usually, no one is designated to have authority to make sure all of them are pursuing the IEP objectives.

There are several things you can do to prevent this situation. First, be sure the IEP clearly states who will be responsible for follow-up; this can be a brief statement on the front page of the IEP. Second, list only two or three important educational objectives in each IEP category. Limit the objectives to your absolute priorities. Remember, the IEP can specify the teaching method or materials to be used. Finally, make sure all professionals who will be working with the child actually read the IEP and are aware of the objectives they should be working toward. 7. Work things out before the annual review. Submit all reports to the committee three weeks before the meeting. Insist that all school district reports be given to you at that time. If there are questions or issues to be resolved, try to work them out before the meeting. The best annual review is a short meeting in which the committee gives approval to

what has already been decided.

Many parents believe that they can obtain an impartial hearing to compensate for their own lack of preparation for the annual review. This is a serious error. A due process hearing will deternine only whether the school district acted in compliance with federal and state mandates. It is not a second chance for the parents to "get it right" by bringing in late reports.

8. *Negotiate*. The process is not an allor-nothing deal. Reasonable negotiation is possible. Several years ago, I wanted my child evaluated by an Alliance for Technology Access center far from my home. The school district agreed to pay for the evaluation and purchase suggested computer hardware. I agreed to pay for our transporta-

tion and lodging.

9. Consider all proposals for inclusion carefully. Federal law requires that children with disabilities be educated in the least restrictive environment. This means including the child in a regular classroom whenever possible. But successful inclusion usually requires support and related services. Sometimes, a school district will include a child without providing needed services. Too often, this is a cost-cutting maneuver which sabotages the child's placement. If you and your school district decide to include your child in a regular classroom, be sure that all teacher training, follow-up procedures, support and related services are provided. 10. Treat the annual review as your most important business meeting of the year. Dress for business. Bring a sufficient number of copies of all documents in case they have not been distributed to all committee members prior to the meeting.

Request a meeting time that permits all adult members of a child's immediate family to attend the annual review. If a child's father is involved with the family, he must attend—I cannot stress this point enough. Request a meeting time that permits his involvement. Meetings are often dominated by women. The presence of the child's father lends credence to the family's full participation in the meeting. Special education is not a women's issue; special education is a family issue.

Barbara J. Ebenstein is a partner in the Law Offices of Harry K. Ebenstein, a family law firm in New York City. She lives with her husband, Dr. John E. Handelsman ("Jack"), and their three daughters, Sarah, 14, Leanne, 11, and Risa, 9.



APRIL 1995 / EXCEPTIONAL PARENT . 63

## ASK THE DOCTOR

by David Hirsch, M.D.

### Hypotonia; Gastrointestinal Problems

Our 14-month-old daughter was recently diagnosed with hypotonia. Her gross motor developmental milestones have been delayed-she did not sit unsupported until one year and she barely stands holding onto furniture now. Her fine motor skills are more age-appropriate, but her language skills are slightly delayed. Our pediatrician has referred us to a neurologist who has done a number of blood and urine tests, an EEG (electroencephalogram or brain wave test) and an MRI (magnetic resonance imaging) of her brain. All these tests have come back "negative." We still do not know the cause of her hypotonia. My daughter's neurologist has indicated that a muscle biopsy may be needed. What do you think?

Hypotonia or low muscle tone, A sometimes called "floppiness in infancy," is not a syndrome or a disease; it is a symptom. There are numerous possible causes of hypotonia in infancy, many of which are very rare. However, most of these causes fall into four categories—disorders of the central nervous system (the brain and spinal cord), disorders of the peripheral nervous system (the nerves that go directly to the muscles), disorders of the neuromuscular junction (where nerves and muscles meet and electrical signals and chemicals are transferred) or disorders of the muscles themselves.

If possible, accurate diagnosis is very important because the diagnosis will influence the treatment, if any. The child's prognosis and any possible genetic implications would also be better understood with an accurate diagnosis.

In your daughter's case, I assume the "negative" tests included the newer types of chromosome testing as well as metabolic testing. Did doctors perform an electromyography (EMG), a test of motor nerve conduction velocities? Is there a family history of hypotonia, or muscle or nerve disease?

A muscle biopsy has become one of the more essential procedures for diagnosing various neuromuscular diseases for which hypotonia is a common symptom. Based on what you have told me, and assuming the other issues we discussed are not helpful in making a diagnosis, a muscle biopsy may be very helpful, especially if your daughter's muscle tone has improved very little during the last six months.

My eight-year-old son suffers daily from stomach pain and gastro-esophageal reflux (the symptons of severe heartburn) for which he has been on various medications (Zantac, Reglan and Propulsid). His esophagus (the muscular tube connecting the back of the throat to the stomach) is chronically inflamed. We have had to seal his permanent teeth to minimize damage from acid reflux and frequent vomiting. He has a small sliding hiatal hernia (the top part of his stomach moves up and down through his diaphragm). Medical tests suggest that his esophageal muscles are weak and uncoordinated.

Our son is very bright but has a learning disability in reading and attention deficit hyperactivity disorder (ADHD) for which he takes Ritalin. These problems frustrate him in school and aggravate his digestive problems. His recurrent vomiting at school embarrasses him. Is there anything else we can try?

This is an example of a situation where one type of developmental or behavioral problem might be making a separate and unrelated physical problem worse. It sounds like you have tried an aggressive medical approach to your son's chronic vomiting with medications that typically work for similar problems. Zantac decreases stomach acid

production. Reglan stimulates motility of the upper gastrointestinal tract, the stomach and the first part of the small bowel. Propulsid (also known as Cisapride) increases the esophageal motility (the ability to push food down the esophagus and keep it in the stomach) and emptying of the stomach. I assume that those medications have been used in the proper combination and dosages. A few other medications, such as Carafate, Urecholine and Prilosec are also available. However, I am not sure if they would be any more effective than those you have already tried.

Your son's pediatrician and gastrointestinal consultant may have to consider other studies to define the most likely cause or causes of his gastrointestinal problems. If it has not already been done, a test called an antroduodenal manometry may be considered. This test assesses the pressures in the lower part of the

continued on opposite page

In this column,
David Hirsch, M.D.,
a pediatrician and
member of the
EXCEPTIONAL
PARENT'S Editorial
Advisory Board,
answers questions
from readers. Dr.

Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with appropriate professionals. Dr. Hirsch mentions specific products or medications only to illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5008, (817) 730-8743 (Fax).

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353

# WHAT'S HAPPENING

#### **Publications**

• Expectations is an annual anthology of children's literature in Braille, for grades three to six. This free publication includes color illustrations with raised edges and a "scratch and sniff" page. Included with each copy is a 1995 calendar printed in both Braille and large print. Contact

Braille Institute Sight Center, 741 N. Vermont Ave., Los Angeles, CA 90029, (800) 272-4553.

• Knowing the Ropes is a 100-page book for parents of children, ages 4 to 15, with speech and hearing impairments. Topics include parents' feelings and supports, deaf culture and alternatives in communication and education. Free to Minnesota parents; \$10 for others. Send payment (payable to the Minnesota Foundation)

for Better Hearing and Speech) to the Parent Network, MFBHS, 166 4th St. East, Ste. 320, St. Paul, MN 55101; (612) 223-5130 (V/TTY)

- Prader-Willi Syndrome—A Handbook for Parents is again available. The book, considered the primary parent-to-parent publication on the syndrome, had been out of print for several years. Order from Prader-Willi Syndrome Association, 2510 S. Brentwood Blvd., Ste. 220, St. Louis, MO 63144, (800) 926-4797 \$6 (\$7 out-ide U.S.), includes shipping.
- Learn how to influence lawmakers and policy with the 32-page booklet *Making Your Case*. One free copy per person or organization is available from the Minnesota Governor's Planning Council on Developmental Disabilities, 300 Centennial Office Bldg., 658 Cedar St., St. Paul, MN 55155; (612) 296-4018, (612) 296-9962 (TTY), (612) 297-7200 (fax). For additional copies, contact Minnesota's Bookstore (612/297-3000, 612/282-5077, TTY).
- Achieving in Spite of ... A Booklet on Learning Disabilities, a practical guide for parents and professionals on helping children with learning disabilities succeed academically and socially, is available from the National Neurofibromatosis Foundation (NNFF). Send \$1 to cover postage and handling to NNFF, 95 Pine St., 16th Fl., New York, NY 10005; (800) 323-7938 (V/TTY).

continued from opposite page

stomach and the first part of the small bowel. Further studies of esophageal motility may also be needed. These tests may be important, especially if more aggressive surgical intervention is being considered. If your son also has had problems with constipation and abdominal distention, doctors need to consider whether he has a condition called "intestinal pseudo-obstruction."

I do not believe that the Ritalin your son takes for ADHD is causing any of his gastrointestinal problems, although this medication can cause abdominal pain and decreased appetite. I also do not think the medications for your son's gastrointestinal condition are affecting the action of the Ritalin significantly. However, any time medication changes are made, your son's doctors and your pharmacist need to consider possible side effects or drug interactions.

It is important to keep your son's teachers informed of his medical condition and the things that seem to aggravate it. Perhaps they can modify his program to decrease the stress he is feeling. Above all, try to be as reassuring as possible to your son.

Special Olympics World Games More than 7,000 ath-

letes are expected to compete in the 1995 Special Olympics World Summer Games July 1–9 in Connecticut at sites in New Haven, West Haven, Hamden, Old Lyme and New London. In addition



Photo courtesy 1995 Special Olympics World Games.

to the athletes, an estimated 2,000 coaches, 15,000 families and friends, 500,000 spectators and 45,000 volunteers from 140 countries will attend the ninth annual World Games.

Sporting events include aquatics, athletics (track and field), badminton, basketball, bocce, bowling, cycling, equestrian events, football (soccer), golf, gymnastics, powerlifting, rollerskating, sailing, softball, team handball, table tennis, tennis and volleyball.

Opening ceremonies take place Saturday, July 1 from 7 p.m.-11 p.m. The games close July 9.

Participation in Special Olympics events is open to individuals older than five years old who have mental retardation or cognitive delays. Children may begin participating competitively at eight years of age.

An important part of the World Games will be the incorporation of Unified Sports, a program that combines an approximately equal number of athletes with and without mental retardation of similar age and ability on teams that compete against other Unified Sports teams.

Founded by Eunice Kennedy Shriver in 1968, Special Olympics' mission is to provide year-round training and athletic competition in Olympic-type sports by providing participants with "opportunities to develop fitness, demonstrate courage, experience joy and participate in the sharing of gifts, skills and friendship with their families, other athletes and the community."

For more information on this event, contact 1995 Special Olympics World Summer Games, 195 Church St., 16th Fl., New Haven, CT 06510; (203) 498-7773, (203) 498-018 (fax).



354

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105	DIESTCO MANUFACTURING .	58
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123	EQUIPMENT SHOP	
31	ESTATE PLANNING	
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135	FORD	
214	FUTURE PRODUCTS CORP .	78
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216	MOBILE TECH CORP.	
76	NEW ENGLAND CTR FOR AUTISM .	
21	NEW ENGLAND VILLAGES	. 75
	NMEDA .	
184	ORALGIENE .	71
12	PLUM ENTERPRISES	
63	RACING STROLLERS	. 33
85	RICON CORPORATION	. 52
41	RIFTON INC	81
162 17	ST Coletta of (MA)	
4	ST JOSEPH'S HOSPITAL & MEDICAL STEWART HOME SCHOOL	66 ENIER
-	TOP END BY ACTION	14
218		C3
102	VANTAGE MINI VANS	/1
108	VOORHEES PEDIATRIC FACILITY	46
215 91	WHEELCHAIR GLIAWAYS WILLOW RIVER FARMS	59
72	WOODBURY PRODUCTS	. 58
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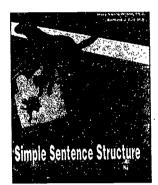
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The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 19,000 products for persons of all ages who have a physical, sensory or cognitive disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers in each listing are to be used on EXCEPTIONAL PARENT'S "Free Product & Information Card." Readers can circle a number on this issue's card (page 63) to get more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).



## HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

# **Cutting Costs** in Medicaid and Medicare

Instead of answering a reader's question in this issue, TROUBLESHOOTER columnist Richard Epstein gives his ideas on how to cut costs in the Medicaid and Medicare programs.

Under the U.S. health care system, many people rely on Medicaid and Medicare to meet the cost of their families' medical care. Medicaid is the only health insurance program for thousands of children with severe disabilities. Medicare serves as the primary insurer for many younger and older adults who have disabilities.

Generally, Medicaid covers children until they are 18 years old; Medicare is for people over 65 or for people who have been getting Social Security disability benefits for two years. Because children, even those with disabilities, do not get Social Security disability benefits until they turn 18, a child usually cannot get Medicare coverage until he or she is 20. However, children with chronic renal disease, who need a kidney transplant or dialysis, are eligible for Medicare.

Federal and state legislators are currently discussing ways to cut funding for these programs. The desire to balance the budget and reduce taxes is understandable. However, Medicaid and Medicare are vital programs.

#### Ways to save

There may be ways to achieve substantial savings in Medicaid and Medicare without cutting essential services. Regulations that govern these programs have become so complex that they may result in unnecessary costs. Changing some rules could result in significant savings.

#### Managed care

Federal and some state governments seem to have concluded that money could be saved if Medicaid recipients are encouraged to switch from traditional plans to managed care programs such as health maintenance organizations (HMOs). However, Medicaid rules in some states appear to discourage recipients from chocsing managed care programs.

When a child with a disability is covered by Medicaid and a parent's traditional group insurance plan, Medicaid generally acts as the secondary insurer. This means Medicaid considers paying any co-pay amounts remaining after the primary insurer has paid its portion of the bill. However, if the parent chooses an HMOs as the child's primary insurer, Medicaid rules in some states appear to prohibit the payment of any co-payments, even when they are significantly lower than they would be if the parent had chosen traditional insurance.

The problem appears to be that HMOs sometimes require co-payments be made *before* services have been performed. Technically, this does not represent an amount remaining *after* the primary insurer's payment.

A great deal of money could be saved if Medicaid paid the co-payments when a child is covered by an HMO and Medicaid.

#### **Medicare changes**

Rule changes could also result in significant savings. The rules determine whether Medi are or a group insurance plan is the primary or secondary insurer are so complex that people sometimes are given the wrong information about which is primary.

When that happens, the error must be corrected through a costly process. It may require that claims be refiled with both Medicare and the group insurance program.

According to a Medicare representative, when a person has a disability, is under 65 years of age and is also covered by a group insurance policy that has more than 100 members, Medicare is generally the secondary insurer:

If the group insurance policy has fewer than 100 members, Medicare is the primary insurer, and the group insurer is secondary. However, there are exceptions to these rules. Simplifying the rules would probably be easier and less costly than trying to correct the errors resulting from these complex regulations.

#### Filing a claim

Other rule changes related to regulations dealing with enforcement provisions, billing, claim determinations and other areas may also result in enormous savings. But perhaps the easiest way to save significant money would be the implementation of a national electronic claim filing and payment system for Medicaid, Medicare and private insurance companies.

The paperwork involved in filing a claim is frustrating, expensive and time-consuming. With computerization, the use of technologically-advanced, electronic "smart cards" could completely eliminate this paperwork.

#### Inefficient situations

Before the government begins to cut services, the first step should be to eliminate the rules that create inefficient situations. This might reduce expenditures so significantly that there would be no need to cut services.

It is important to write to state and federal legislators to demonstrate the importance of Medicaid and Medicare. You might suggest the approaches discussed in this column as: a way to reduce costs. **EP** 

In this column, Richard
Epstein answers readers'
questions about health
insurance. Send your questions to him at Exceptional.
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to a specific ease include who received not offices.

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your imitials and state will be published. It is not possible to respond to letters included.



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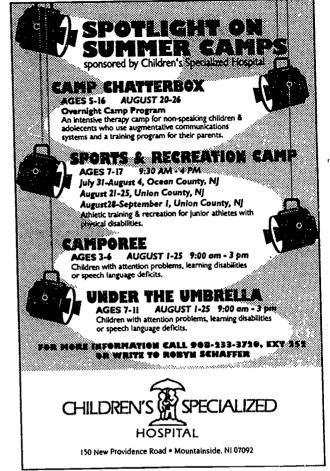


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#### \ California

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#### **₄Connecticut**

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Annandale Village 3500 Annandale Lane Suwanee, GA 30174 (404) 945-8381 Private, nonprofit community for adults with developmental disabilities. Full residential, day, and evening programs and services promote we'll-balanced lifestyles which include a broad range of activities. Located on 125 wooded acres near Atlanta. See ad on page 77

#### Illinois

Ailendale School PO Box 1088 Lake Villa, IL 60046 (708) 356-3334 Allendale School is a special education program providing comprehensive services to youths with emotional/behavioral disabilities.

#### Kansas

Heartspring

2400 Jardine Drive Wichita, KS 67219-4699 (316) 262-8271 Heartspring serves students ages five through 21 who have multiple disabilities and communication disorders. We serve residential school and day-only students. Outpatient assessments, short-term treatment programs, and hearing center services are also offered

See ad on page 6. Circle #6

#### Kentucky

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#### Maryland

The Harbour School 1277 Green Holly Drive Annapolis, MD 21401 (410) 974-4248 Serves LD & multi-handicapped children ages 5 through 21. Services include counseling, OT, job training & a HS diploma.

#### Massachusetts

**Cotting School** 453 Concord Avenue Lexington, MA 02173 (617) 862-7323 Cotting School welcomes boys & girls ages 3-22 with physical, medical, learning & communication disabilities. We offer individualized academic, pre-vocational and social experiences to build confidence & enhance students' self esteem. See ad on page 57

The Ivy Street School

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Latham School; R.R.C.I. P.O. Box 1879 1646 Main Street Brewster, MA 02631 (508) 896-5755 Special education / residential facility for girls ages 8-22 with mild dev. delays and ED/BD Contact: Shirley Landers-Pfautz

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See ad on page 28

League School of Boston 225 Nevada Street Newtonville, MA 02160 (617) 964-3260

The Learning Center 411 Waverley Oaks Road Waltham, MA 02154 (617) 893-6000 Children and young adults with MR, autism, communication disorders, challenging behaviors, developmental disabilities, 12 mg. day/residential. See ad on page 77

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New England Villages, inc. 664 School Street Pembroke, MA 02359 (617) 293-5461 Exceptional private community for MR adults offering a range of residential options, vocational, recreation and social opportunities. See ad on page 59

St Coletta's of Massachuse'ts Cardinal Cushing School and **Training Center** 400 Washington Street Hanover, MA 02339 (617) 826-6371 See ad on page 81

#### **New Jersey**

Githens Center 40 Cedar Street Mount Holly, NJ 08060 (609) 261-1667 Providing a school; DT, PT, ST, day care; respite; medical services; adult activities and family support for individuals with physical and other disabilities.

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for Down Syndrome Edmeston, NY 13335 (607) 965-8377

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See ad on page 44

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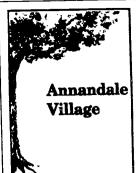
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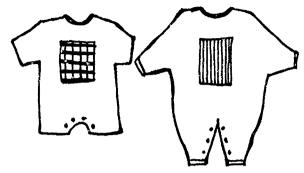
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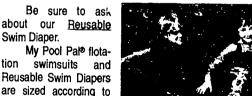




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# Networking

### Information from The National Parent Network on Disabilities

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Patricia McGill Smith Executive Director

## **Change on Capitol Hill**

SEN. FRIST NAMED CHAIR OF DISABILITY POLICE SUBCOMMITTEE

Sen. Bill Frist, R-Tenn, is the new chairman of the Disability Policy Subcommittee of the Senate Labor and Human Resources Committee. The freshman senator, a 1974 graduate of Princeton University and 1978 graduate of Harvard Medical School, is a Nashville surgeon specializing in heart and lung transplantation.

At the Vanderbilt University Medical Center's Vanderbilt Transplant Center, which he established in 1986, Frist pioneered innovative diagnostic techniques and performed the first pediatric heart transplant and first lung transplant in Tennessee. The author of more than 100 articles and abstracts on medical research and policy, Frist has also published *Transplant*, a 1989 book examining the social and ethical issues of transplantation.

Frist received the Distinguished Service Award from the Tennessee Medical Association in 1992 for his efforts in successfully organizing a grassroots campaign to return the organ donation card to the Tennessee driver's license. That same year, he was asked by then Gov. Ned McWherter to serve as chairman of the Tennessee Task Force on Medicaid.

Sen. Tom Harkin, D-IA, the subcommittee's former chairman, remains a subcommittee member.

## MORRISSEY NAMED STAFF DIRECTOR OF DISABILITY POLICY SUBCOMMITTEE

Patricia A. Morrissey, Ph.D. has been hired as the staff director of the Senate's Disability Policy Subcommittee, chaired by Sen. Bill Frist, R-Tenn. A graduate of Hartford Community College, Stetson University and Pennsylvania State University, Morrissey is a long-time disability-rights advocate and government worker, having held positions at the House Committee on Education and Labor, Rehabilitation Services Administration in the Office of Special Education and Rehabilitative Services and General Accounting Office.

Most recently, Morrissey was vice president of Government Relations for Community Programs and governmental relations specialist at the law firm of McGuiness & Williams. From 1991 to 1994, Morrissey was vice president of Employment Advisory Services, Inc., where she advised corporate, public and federal clients on federal disability policy. She also served as a technical advisor to and appeared in commercial training videos on the Americans with Disabilities Act (ADA).

Morrissey is the author of several books on disability-related topics, including the Employment Policy Foundation's Disability Etiquette



Sen. Bill Frist, R-Tenn, the new chairman of the Disability Policy Subcommittee.

in the Workplace, the Vocational Education Association's Educator's Guide to the Americans with Disabilities Act and LRP Publications' A Primer for Corporate America on Civil Rights for the Disabled and Employer's Guide to the Americans with Disabilities Act.

# REP. CUNNINGHAM HEADS SUBCOMMITTEE ON EARLY CHILDHOOD, YOUTH AND FAMILIES

Rep. Randy "Duke" Curningham, R-CA, has been named chairman of the House's Early Childhood, Youth and Families Subcommittee. This subcommittee has jurisdiction over the reauthorization of the Individuals with Disabilities Education Act (IDEA). The subcommittee's ranking minority member is Rep. Dale Kildee, D-MI. Hans Meeder will serve as the key staff member to this subcommittee as well as to the full Economic Opportunity Committee, previously known as the Education and Labor Committee, chaired by Rep. William F. Goodling, R-PA. The ranking minority member on the full committee is Rep. William Clay, D-MO.

#### **Legislative Update**

## SENATE SETS IDEA REAUTHORIZATION CALENDAR

Patricia A. Morrissey, staff director of the Senate's Disability Policy Subcommittee, has issued a tentative schedule of events for the reauthorization of the Individuals with Disabilities Education Act (IDEA):

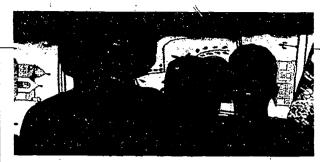
- Immediately: One-year extension of IDEA, Parts C through H.
- May 1995: Two days of informational hearings on the education of students with disabilities.
- June 1995: Four days of briefings for subcommittee staffers.
- Fall 1995: Reauthorization bill drafted, two continued on page 80



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368

APRIL 1995 / EXCEPTIONAL PARENT . 79



Gail Johnson with sons Eric Jr., 13, and Isaiah, 9. Johnson and her husband, Eric, also have a daughter, Ain, 19.

#### **New Staff Announcement**

NPND is pleased to announce that Gail D. Johnson joined the staff in January as development and program specialist. Her chief responsibilities are the Toys "R" Us Project which includes the third edition of the Toy Gu. de For Differently-Abled Kic's due to be released this spring, development of special projects and providing members with parent-to-parent support and information, including information on legislative activity directly related to families of children with special needs.

Johnson, a mother of children with special needs, was formerly the Coordinator of the Association for the Care of Children's Health (ACCH) Parent Network, a national network of approximately 2,000 parents and family members of children with special needs.

For the past seven years, Johnson has been a speaker and consultant for many state and national programs on topics including family and professional collaboration, parent-to-parent support and networking, cultural competency and parenting children with special needs. She frequently presents workshops and conference talks to parents and professionals about family-centered, community-based and culturally-competent service delivery.

continued from page 79

days of reauthorization hearings and mark-up of the bill.

• November 1995: Senate floor debate on bill.

The House may have a similar schedule and may hold joint hearings with the Senate in the spring.

In conjunction with the Consortium for Citizens with Disabilities, the National Parent Network on Disabilities (NPND) has agreed to lead the identification of issues and the development of a panel to describe how schools can be most responsive to families. This work is anticipated to shape the reauthorization hearings in the spring and summer.

#### OSERS RELEASES "VISION" PAPER

In February, the Office of Special Education and Rehabilitative Services (OSERS) released a draft of its "vision" paper outlining its proposal for the reauthorization of IDEA. This draft of the paper is intended for review by interested groups and organizations. NPND has had extensive conversations with Judy Heumann, assistant secretary of OSERS, and Tom Hehir, director of the Office of Special Education Programs (OSEP), concerning the preliminary drafts of the paper, which will eventually become the Clinton administration's recommendations for IDEA reauthorization.

As Exceptional Parent went to press, an updated draft of the proposal was slated to be issued in late March.

Copies of the proposal are free. Contact OSEP, 600 Independence Ave., SW, MES Building, Rm 3086, Washington, DC 20202-2570, (202) 205-5507 (voice), (202) 205-9754 (TTY), (202) 260-0416 (fax), or request a copy through the Internet at thomas_hehir@ed.gov.

#### UNFUNDED MANDATES

The House and Senate has passed unfunded mandate legislation, which limits Congress from imposing mandates on states without authorizing federal funds to help with their implementation.

Through the efforts of the Family Action Network (FAN) to Save IDEA, NPND's special project in which FAN members contact legislators on key issues, we have received letters from Rep. William F. Goodling, R-PA, Sen. Dick Kempthorne, R-ID, and the Congressional Research Service stating that IDEA and the Americans with Disabilities Act (ADA) will not be dismantled because they are not considered unfunded mandates. These assurances will be of great importance as the reauthorization of IDEA proceeds.

#### CORRECTIONS DAY

The National Governors' Association (NGA) has written to House Speaker Newt Gingrich requesting that IDEA be modified, even before reauthorization, during "Corrections Day," a yet-to-be-announced day proposed by Gingrich for the House to "fix" the technical aspects of any law "in need of fixing." NGA has asked the House to review several issues related to IDEA, particularly at ways to give states more flexibility in the spending of IDEA funds.

NPND opposes any attempts to amend IDEA before the reauthorization process takes place. NPND has alerted members about this through its Fax Tree program and in a FAN alert. For more information, contact NPND, 1600 Prince St., Ste. 115, Alexandria, VA 22314, (703) 684-6763 (V/TTY), (703) 836-1232 (fax).

# A Parent's Perspective on Bright Futures

Bright Futures: Guidelines for Health Supervision on Infants, Children, and Adolescents, a guide supported by the federally-funded National Center for Education in Maternal and Child Health, not only talks about the integration of health services with child development, human services and education, but it actualizes a family-centered, culturally sensitive, community-based approach to provide care to children and their families. This comprehensive guide equips health care professionals with techniques that put families in the "center ring," enabling families to be meaningful participants in the care of their children. Cost is \$22.35 (includes shipping and handling); bulk discounts are available. Order from National Maternal and Child Health Clearinghouse, 8201 Greensboro Dr., Ste. 600, McLean, VA 22102, (703) 821-8955, ext. 254 or 265, (703) 821-2098 (fax).

For more information about *Bright Futures* other than ordering, contact National Center for Education in Maternal and Child Health, 2000 15th St. N, Ste. 701, Arlington, VA 22201-2617, (703) 524-7802, (703) 524-9336 (fax).

---Galf D. Johnson



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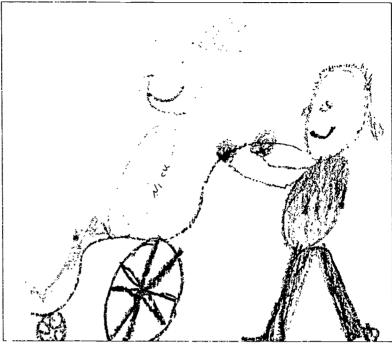
# CHILDREN'S PAGE

# I LOVE MY BROTHER

by Ivan G. Smith

y brother's name is Nick. He is 10 years old. His birthday is January 2. Nick has cerebral palsy. That means his muscles don't work like mine.

Sometimes, we play together in the tent we put up in our backyard. I like to play



Drawing by Ivan G. Smith

school with Nick. He doesn't always want to do math because he's not very good at it. Nick says he hates school, but he really likes it.

Nick has a wheelchair and walker to walk. We have a wheelchair ramp in our van. If Nick didn't have cerebral palsy, we wouldn't have the van.

Nick and I don't go to the same school, but someday we might. I love Nick a lot. EP



Ivan G. Smith, 7, lives with his parents, Nancy and Rodney, and his brother, Nick, 10, in Bradford, Massachusetts. Ivan enjoys writing, drawing, reading and baseball. He is a second-grader at the Greenleaf School in Bradford. Nick attends a special education program at the Frost School in Lawrence, Massachusetts.

Nick and Ivan Smith, just before leaving for school one day last year.

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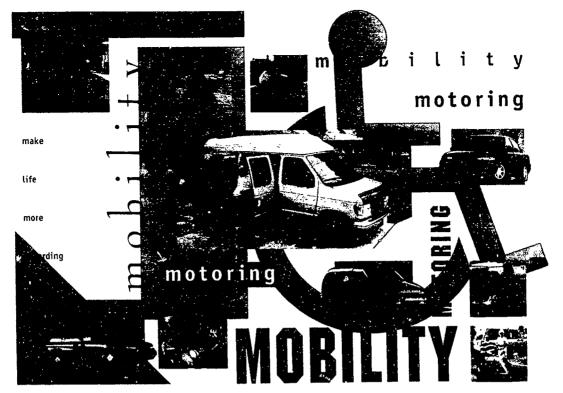
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# EXCEPTIONAL DARENT

MAY 1995 VOL. 25, ISSUE 5

The Magazine for Families and Professionals

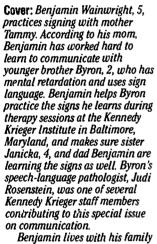
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CHILD OR YOUNG

ADULT WITH A

DISABILITY

Since 1971



Benjamin lives with his family in Edgewater, Maryland. He attends Hillcrest Elementary School and enjoys playing outside on his swingset. Photo: Robert Smith Jr.

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10



PAGE 22

#### COMMUNICATION

Saying it a Different Way by Judi Rosenstein and Jan Turner	21
"Problem behaviors" may be a means of communication	
·	
Turn-taking: A Giant Step to Communicating by James McDonald	2/1
Becoming Andrew's Playmate by Pam Rodawalt	
"GET UP! GET UP!" by Barbara Coo	20 ac
Making Turn-taking Fun by Barbara Mitchell	
Seven Years of Turn-taking by Jan Daily	21
Hearing Impairment & Hearing Aids by Joseph P. Pillion	30
Getting Started with Augmentative Communication	
ty Naomi Angoff Chedd	34
Facilitated Communication: What Parents Should Know	
by Karen Levine and Robert Wharton	40
An FC Nightmare by Cecilia Johnson	40
Speaking with Kimberly by Marilyn Dixon	
FACILITATING LOVE by Lewis Johnson	4 <u>Z</u>
FROM SOMEONE WHO'S BEEN THERE AND BACK by Janyce L. Boynton	
Using the Telephone by Susan Phillips	55
Departments	
Editor's Desk	
Letters	
Search & Respond	
Fathers' Voices: Crisis by Galen Lowe	
Role Models: Themas E. Strax	
Familiar Faces	
What's Happening	
Directory of Advertisers	
Media: Taking Charge	
Ask the Doctor: "SMART DRUGS;" UNDIAGNOSED	
New Products	
Exceptional Parent Library	
	76

# EDITOR'S DESK

#### **Controversial topics**

This issue of *Exceptional Parent* deals with several topics that arouse much controversy and emotion on the part of parents and professionals. As part of our look at communication, we present several perspectives on facilitated communication (FC).

And, in his regular department, *Ask the Doctor*, David Hirsch, M.D., discusses the controversial topic of "smart drugs."



STANLEY D. KLEIN, PH.D.

Both topics have received a great deal of media attention, and as I meet with parents and professionals in my travels, I am often asked about them. Such questions typically come from dedicated, caring parents who are troubled and angry about the opposition of many professionals to FC, "smart drugs" or other relatively new approaches. Each time I speak with one of these parents, I remember the movie *Lorenzo's Oil*, the true story of courageous parents who struggled to find answers for their son without the support of the health care establishment. But at the same time, I

look back some 40 years and remember my first experience with one of these "breakthroughs." In that instance, a consulting psychologist demonstrated that a youngster with severe physical disabilities and no understandable speech was *not* consistently responding "yes" or "no" to the questions I—and others—thought he was answering. It was shocking and demoralizing to realize we had wished so hard for the youngster's success that we had tricked ourselves into believing it was so.

Several years later, as a beginning clinical psychologist, it was my sad task to demonstrate that a different child could not actually read the word "mother" as her parents and teacher believed. Instead, she said "mother" any time she saw the letter "M"—upside-down, sideways, and with any other scribbles nearby—just as she did when she saw the letters "m-o-t-h-e-r."

Some truths are clear and will never change—parenting is hard work and parents will do whatever they can on behalf of their children. All of us—parents and professionals—are human, make mistakes and are inconsistent, because life is like that. We work each day on behalf of children and young adults with disabilities with as much hope and strength and wisdom as we can muster—and, yes, we wish for miracles.

Over the years, I have listened with wishful interest and respect to reports of "miracles"—diets, for example, that claimed to dramatically alter mental retardation or mental illnesses. Each time, although it seemed a few individuals appeared to benefit from these treatments, most did not. And the proponents of these "miracles" were unable to explain their failures—except, sometimes, to blame parents for not carrying out instructions properly. Despite these experiences, when I first witnessed FC and heard reports of this communication breakthrough, I hoped—somehow—it was true.

The reading and research we did in preparing this issue has convinced us that FC is not a valid approach to communication. Nonetheless, we have included reports from readers who believe FC has been helpful for their children. Similarly, I have invited Syracuse University professor Douglas Biklen, who introduced FC to the United States and remains a proponent, to comment in a future issue. Some readers may find this inconsistent, even confusing. But this magazine remains open to parents and professionals with differing opinions. I have known Doug Biklen for many years and respect his dedication and caring; we also respect the observations of parents who believe FC works for their children. Our mission is to inform our readers as completely as possible. We trust that the information we provide gives both parents and professionals the power to act responsibly and with compassion.

—S.D.K.

As the academic year draws to a close, we say farewell and extend thanks and best wishes to three fine journalism intems from Boston University—Andrea Kamens, Jennifer Koerber and Michele San Filippo—who have helped us in many ways for many months. Congratulations on your graduation. We also welcome two new editorial staff members, Slobhan Mullins and Naomi Chedd.



Entron in Charl Stanley D. Klein, Ph.D. Professor of Psychology, New England College of Optometry

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# LETTERS

#### "All Together, Now!"

Many articles have made me want to sit down and write you, but after reading "All Together Now," the guest editorial by Justin Dart (February 1995), I finally did. This piece should be a warning cry to your readers that we must not become complacent with respect to hard-won gains made on behalf of people with disabilities.

I worked for two congressmen in the 1970s, and have always followed the political scene closely. I believe that politics is the art of compromise, but today's political climate seems to lack the kind of give-and-take that is necessary to move ahead. It is disturbing to think that the majority party in Congress could seek to undermine the basic rights of our loved ones.

K.C., Maryland

■ I could not agree more wholeheartedly with Mr. Dart. It is of crucial importantance that we all voice our opposition to any congressional actions designed to weaken the American with Disabilities Act (ADA), the Individuals

with Disabilities Education Act (IDEA) or any other statutes protecting children and adults with disabilities.

Today's legislators should understand that Congress passed IDEA—the law ensuring that children with disabilities receive a public education—as a cost-saving, not a cost-incurring, statute. The entire purpose of IDEA was to enable our children to develop into economically productive citizens of our society. Let us work together for victory in this watershed legislative session of the United States Congress.

J.P.G., Tennessee

#### **Child Care**

I am the inclusion/special needs representative for the Arrowhead Association for the Education of Young Children, an affiliate of the National Association for the Education of Young Children. I have assisted in daycare centers and preschools and was a preschool teacher for a short time. I am also an experienced respite care provider.

The entire February issue really got

me excited. I immediately started to write to some of the organizations listed in the resource directory so I could make contacts for information.

I love your magazine!

 ${\it J.E., California}$ 

■ I want to commend you on the wonderful job you did with the articles on early childhood (February 1995). The magazine provided a lot of really useful information, and the stories from real families about their child care experiences were superb.

I want to correct several statements in "Child Care and the ADA." First, with regard to the "direct threat" exception—in the ADA regulations on "public accommodations"—a child may be excluded only if he or she poses a threat (defined as "a substantial risk of harm") to others; a child cannot be excluded because of risk to self. This confusion has arisen because the ADA regulations dealing with employment allow the exclusion of individuals who pose a risk to themselves.

It is also a bit misleading to say that

continued on page 6

# EXCEPTIONAL PARENT

To reach out to parents of children and young adults with disabilities and special

health care needs and to the professionals who serve families

To empower parents and professionals by providing practical information and emotional support.

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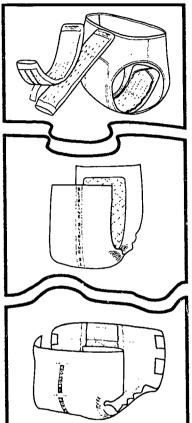
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continued from page 4

to exclude a child for this reason, a child care provider "must document efforts made to include the child." Any decision about excluding a child must be made using objective information—such as medical information—not sheer speculation. If the threat of harm can be eliminated through reasonable accommodations in the program, this must be done. In any case, the "direct threat exception" is a very narrow one, and will not ordinarily be considered a proper basis for a child care program to exclude a child.

As you mentioned in the article, the Child Care Law Center provides a number of publications on this topic. I wanted to add that all publications are also available in Spanish.

Abby Cohen, Managing Attorney Child Care Law Center 22 Second St., 5th Fl. San Francisco, California

#### Happy, But He Shouldn't be Wet

Words cannot express the sorrow I feel for Marcia Todhunter and her family ("Wet, But Happy," February 1995). I don't feel this sorrow because Todhunter's son, Ben, has severe disabilities, but because the family has encountered a person who has the worst disability of all—intolerance.

My six-year-old son is still in diapers. I have met some very ignorant check-out clerks at our local retail store where I buy diapers, but the administrator in Ben Todhunter's day care program really takes the cake!

Even if this school program is not included as part of Ben's IEP, Todhunter still has a tool she can use on her son's behalf. It is the Americans with Disabilities Act (ADA). The ADA states that public accommodations, including child care centers, must make reasonable modifications in policies, practices and procedures to accommodate individuals with disabilities. Helping a child with toileting should be consid-

ered a reasonable modification. It sounds like the staff is willing to help this child; if so, they should stand up to the administrator and let her know she is wrong.

I am glad Ben is happy in this program and that he is doing so well, but he should not be wet.

M.P., Illinois

#### Thanks for "Hop On!"

We were thrilled and inspired to see Stephanie Royster's story ("Hop on!" March 1995). Like Stephanie, our three-and-a-half-year-old daughter, Kelly, also has spinal muscular atrophy (or Werdnig-Hoffman disease). Kelly got her power chair when she was three and quickly mastered it. It was wonderful to be able to show her another child who is in the same situation.

D.G., Michigan

#### **Professional Praise**

Although I am a professional (a teacher of children with severe disabilities), I find *Exceptional Parent* much more interesting and informative than many "professional" journals. Keep up the good work.

C.H., Florida

#### **Fathers' Voices**

I have really enjoyed the Fathers'
Voices column in Exceptional Parent.
It makes me feel more like a real percontinued on page 8

#### Tell us about...

ا حة بده

...your views on and experiences with various educational options (inclusion, special schools, etc.).

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.





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MAY 1995 / EXCEPTIONAL PARENT • 7

continued from page 7 son to see so many of my thoughts and feelings put into perspective. I certainly appreciate James May's efforts.

T.C., Nebraska

**Inspiration for a Support Group** 

My seven-year-old daughter is beautiful, energetic and loving. A birth injury left her with moderate mental retardation, a severe seizure disorder, attention acticit hyperactivity disorder (ADHD) and sensory integration disorder. She was not diagnosed until the age of five because she has always been very healthy and in her birth records, the hospital neglected to mention that she was without oxygen for 15 minutes after birth.

I began reading Exceptional

Parent when my daughter's disabilities were first diagnosed. A wonder-

ful doctor gave me my first copy. It has been an excellent resource—very informative, even heartbreaking at times. I have yet to read an issue that doesn't bring tears to my eyes. The magazine has helped reduce my feelings of isolation, fear, self-pity and grief. It has given me the strength and courage to do what is necessary to improve the quality of life for my family.

We live in a rural area, about 70 miles north of Minneapolis. Resources in Minneapolis are inaccessible to us due to distance. I had been looking for a parent support group for two years but could not find one within a 50-mile radius of my home. After reading the September 1994 issue focusing on education, I was inspired to begin my own support group. I announced it in a letter

to the editor of our local newspaper and our first meeting was held in October. Nine people attended three parents of older children, four parents of younger children and two special education teachers in our school district.

Many professionals have offered their services to lead discussions of topics ranging from accessing services to dealing with feelings of grief and loss. We plan to form a sibling support group and organize social events. The school district has asked me to write an article about the group in their monthly newsletter.

I would like to help make your magazine more available to families in this community. I don't want to part with any of my issues because I reread them often.

J.L., Minnesota

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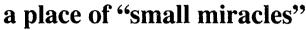
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Throughout all the programs at Berkshire Meadows is a commitment to improving each young person's ability to communicate. For most of these young people, there has been no incentive to communicate: their basic needs have been provided for, in one way or another, and they have in any event been unable to express needs or wants in ways that other people understand. So the first task is to motivate communication, which we do by offering choices - of toy, snack, drink, etc. By using pleasurable choices and consequences, we provide even greater incentive to the child to break through his or her passivity.

In general, the Berkshire Meadows staff use Total Communication with all the students – that is, we use a combination of sign language, facial expressions and words. However, for many of our students using normal sign language is not feasible, so we develop individual augmentative communication skills. We teach the use of mechanisms such as object displays, switch-operated scanning devices and VOCAs (voice output communication aids) ranging from simple, pre-programmed devices to sophisticated computers with speech synthesizers. Once a system of communication has been established, we ensure that family members and all staff are trained to understand it, so that the student is spared the repeated frustration of not being understood.

Concomitant with learning to communicate is the ability to impact one's own life. For the youngsters at Berkshire Meadows, this is a primary step toward psychological development and emotional wellbeing. We believe that all children, no matter how severely disabled or mentally retarded, can make progress, and that through careful assessment of all aspects of development, con. lered planning and teaching, round-the-clock structure, and a nurturing environment, children can achieve their maximum potential.

For further information, please contact: Gail Charpentier, Executive Director, Berkshire Meadows, 249 North Plain Road, Housatonic, MA 01236 (413) 528-2523



# SEARCH

#### Alpha-Mannosidosis; Telling a Child About her Disease

My 10-year-old daughter has been diagnosed with alpha-mannosidosis. This is one of the lysosomal storage disorders, progressive diseases in which a defective enzyme causes biochemicals (in the case of alpha-mannosidosis, oligosaccharides) to be stored—rather than metabolized—in the body. Alpha-mannosidosis is similar to mucopolysaccharidosis (MPS), but much rarer, affecting only a few hundred people in the U.S. There is no known treatment.

My daughter has been diagnosed with alpha-mannosidosis, type II, a "milder" juvenile form. Her immune system is probably affected; she is undergoing testing to confirm this. She also has a bilateral hearing impairment, learning disabilities, mild mental retardation and many physical difficulties.

I would like to hear from anyone who has information on alpha-mannosidosis, or who knows other families dealing with this disease. I would also like to hear how other parents have approached the delicate situation of explaining a disease like this to a child—when have you found it appropriate to do so, and how much information did you volunteer? My ex-wife and I have found it hard to agree on what to tell our daughter. I'd especially like to hear from other divorced parents dealing with this issue. How have you handled it, and how did it work out?

P.M., Georgia

#### **Colorful Brace Stockinettes**

My daughter is almost four years old and wears bilateral KAFO's (knee-ankle-foot orthoses). She uses "brace liners," cotton stockinettes that absorb perspiration and prevent the plastic part of her braces from sticking to her legs. Although young, my daughter is quite fashion-conscious and wants leggings in different colors. We've tried tights, but because the braces cover her thighs, tights make diapering/toileting difficult. Does anyone know a source for colorful brace stockinettes?

E.L., New York

#### **Born Without Arms**

My 18-month-old daughter, Kayla, was born with amblia of the upper extremities; in other words, she was born without arms. This is a rare physical disability occurring once in every 450,000 births. Experts believe Kayla's disability has no specific cause or origin; it just happened by chance.

I am looking for families who have a child with this or a similar disability who can give us insight and support. We would appreciate any correspondence.

P.B.A., Louisiana

EDITOR'S NOTE: SUPERKIDS NEWSLETTER (60 Clyde St., Newton, MA 02160) is a terrific publication full of useful information and stories from families and kids who have limb disorders like your daughter's. Subscriptions are free (two issues per year). To help families of children with similar limb disorders find each other, SUPERKIDS also publishes a directory; \$12 for families, \$17 for professionals (includes postage).

# Partial Trisomy of Chromosome One

Our 16-month-old daughter has partial trisomy for a portion of the distal long arm of the first chromosome. Ashley was born with a club foot; a CAT scan showed that the corpus callosum portion of her brain did not fully develop. She currently receives physical therapy and speech therapy; most of her motor skills are at a six-month-cid level.

The doctors tell us this is a very rare condition. We have been unable to locate any other children with this chromosomal abnormality. We would like to hear from anyone who has any information about this condition.

S.P. & S.P., North Carolina

#### **Dealing with Seizures**

My wonderful son, Christopher, is almost three years old. He scoots around on his behind and is just starting to stand by holding onto furniture. His speech is limited to cooing and babbling.

In July of 1993, Christopher had an

MRI which showed that he had cerebral dygenesis; meaning roughly half his brain is gone. He has had a normal EMG, and an abnormal EEG. Chromosome tests have been normal.

Christopher has developmental delays, hypotonia (low muscle tone; mainly on the left side), slightly clubbed feet, farsightedness and a seizure disorder. His seizures are controlled, for the most part, by Dilantin. But now, when he does have seizures, he stops breathing.

Are there any other children out there like Christopher? I want to know how other parents deal with the seizures. In particular, how do other parents sleep at night? Christopher is on a monitor right now, but it's showing he has some apnea. I want to know how far this might go, and what we can expect. Right now we don't have many answers and it would be nice to know that we are not alone.

D.R., Wisconsin

#### **Adams-Oliver Syndrome**

I'm a 21-year-old mother in search of information on a rare genetic disorder known as Adams-Oliver syndrome, which involves congenital scalp, skull and skeletal defects. My one-year-old daughter was born with aplasia cutis congenita on the top of her head; this means that the skin in that area did not develop. That has healed over. In addition, her toes are very short.

My daughter's case is unique because she has severe brain damage—not typically associated with this syndrome. However, doctors say that her brain damage may be related to the syndrome, occurring as a result of deformities of the veins in her brain.

My husband and I have done as much research as we can. We know there have been only 40 cases of this syndrome reported since it was first diagnosed in 1945. Some of these cases included vascular deformities, but none as severe as our daughter's. We are looking for any information that may help us help our daughter.

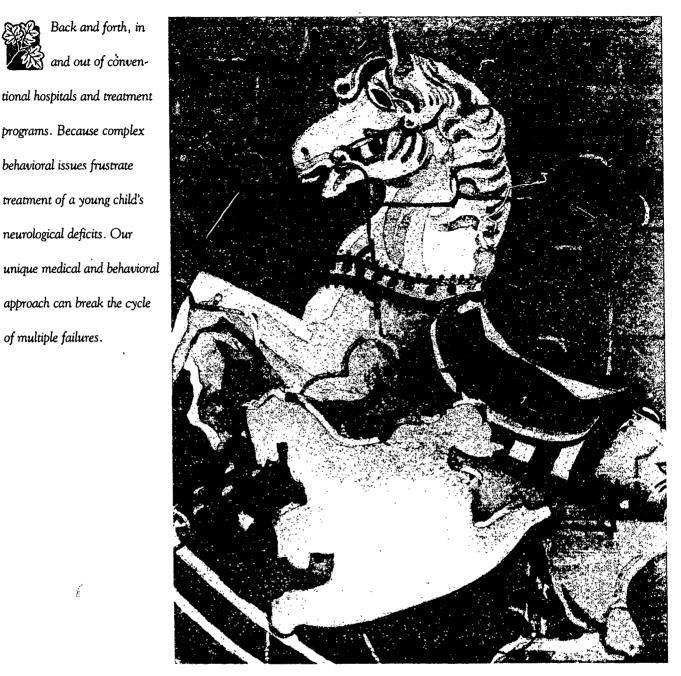
E.L., Arkansas

continued on page 12

Back and forth, in and out of conventional hospitals and treatment programs. Because complex behavioral issues frustrate treatment of a young child's neurological deficits. Our

approach can break the cycle

of multiple failures.



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#### SEARCH

continued from page 10

#### Kartagener Syndrome

I am the mother of a five-year-old boy who has inmotile cilia syndrome, also known as Kartagener syndrome, a genetic disorder characterized by chronic sinusitis and respiratory problems.

My son gets frequent respiratory infections and is often hospitalized to have intravenous antibiotics. He has asthma and a speech delay.

My husband and I have not found any other families dealing with this syndrome or many doctors who know much about it. We are looking for any information, and contact with other families to start a support group.

B.U., Michigan

#### Chromosome 10p-

We have a two-year-old son, Jake, who has been diagnosed with a P deletion of chromosome 10. Jake has a severe hearing impairment, multicystic dysplastic kidney disease and global developmental delays.

We are seeking information about the tenth chromosome—what information is stored there and what are the effects of a deletion? I want to hear from other families who have dealt with abnormalities involving chromosome 10.

J.S., California

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax: Search or Respond, Exceptional Parent 209 Harvard Street, Suite 303,

Brookline, MA 02146-5005 Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in Exceptional Parent's 1995 Resource Guide (January 1995).

# RESPOND

#### **Loud Noises in Public**

G.W. & J.W. (December 1994) have a six-year-old daughter, Kaitlyn, with severe intellectual disabilities. Kaitlyn does not talk, but makes loud noises and high-pitched screams; her parents worry about how these noises will be handled when she starts kindergarten next year. They wanted to hear from anyone who has dealt with a child who has similar characteristics, and were especially interested in suggestions for getting Kaitlyn's noises "down to a reasonable pitch."

I began to write to you after reading your letter, but with our busy lives, I set my response aside and never finished it. I wish I had, especially after reading the response that was published in the March 1995 issue. D.T. from Texas, whose daughter also screams in public, said she and her husband had decided against forcing their daughter to modify her behavior—"These screams are [her] only means of communication... This is one area where society will have to make the adjustments." I'd like to offer another opinion.

Our son, Danny, will be five this summer. Like your daughter, Kaitlyn, he enjoys picking things up and dropping them. He also has a constant need to touch things and bring them to his mouth. Danny is unable to speak; when he becomes frustrated, he bites his shirt. He also screams a high-pitched scream.

Danny began screaming when he was a year old. As he got older, the screaming became louder and more frequent. I would have loved to have said, "Well, society can just deal with it," unfortunately, society and our education system don't work that way.

Danny attends a special school that is part of the public school system. You can imagine how thrilled we were when his teacher told us he felt Danny was ready to attend a preschool class. We thought, "He's on his way now." He began the transition by attending this class every Friday for a month.

My heart sank when Danny's teacher told us that the preschool

teacher felt Danny's screaming was disruptive to the other children; she was not sure he should attend her class fulltime. I knew that by law, Danny had a right to attend her class. But why would I want someone teaching my son when she felt he was a burden?

On a routine visit to the doctor, Danny started his screaming. The doctor asked if this is what we had been telling him about for the past three and a half years.

I said it was.

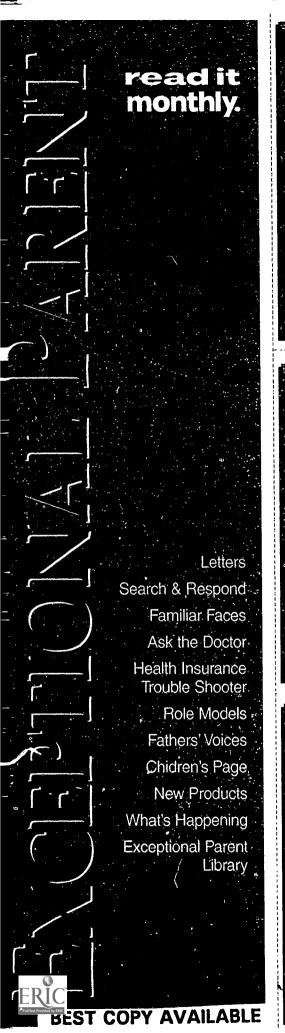
The doctor said he wanted to try something. He turned Dan's chair to face him and used a strong tone to tell him that screaming was inappropriate behavior.

I was appalled. We had been going to this doctor for almost five years; he knew the screaming was Danny's only way of communicating. But then I realized that Danny had stopped screaming as soon as the doctor reprinanded him.

After that doctor's visit, my husband and I took a long, hard look at ourselves and the way we disciplined our son. We asked ourselves if Dan understood us. The answer was "yes." Then we asked whether we would allow our other three children to som un or make loud noises for no apparent reason. The answer was "no."

We realized we were treating Danny differently because of his special needs. So we began to give him a time-out every time he screamed, by putting him in a chair. This was very hard for us to do. Every time I placed him in the chair, my heart would break.

It's been four months since we started doing this. Now, Danny only screams once in a while. When he does, I can tell him that if he screams again, he'll get a time-out. Normally, he won't scream again. This also works in public. If I warn him, he'll stop. If he screams again, he gets a time-out. His teachers are amazed at the difference in his behavior. Very rarely does he scream at school because they also have a time-out chair.



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III....li...lli.di...lli.di.di.di.....llidi.dli...l

BEST COPY AVAILABLE

The best part is this: now that we no longer accept Darny's screaming as communication or as part of his disabilities, he has started to use sign language. He now signs "yes" and "no," and when he wants our attention, he uses appropriate ways of getting it.

This may or may not help you; every child and family is different. I don't know you or Kaitlyn, but I thought you might like another idea instead of just expecting others to accept her screaming. I love my son with all my heart and want all the opportunities in the world for him. I learned that by letting Danny scream, I was taking some of these opportunities away from him-opportunities to make friends, to communicate better with the people around him and to learn in a regular classroom. I don't feel like we made our son conform to society's standards, but that we taught him he must behave at home and in public in the same way we expect our other children to behave. He has grown from this experience, and so have we.

D.B., Micnigan

#### Undiagnosed

D.N. (March 1995) was seeking a diagnosis for her three-year-old daughter's condition. Amanda was born with extremely low muscle tone, dislocatable hips and hypermobile joints. She began walking independently with the use of ankle-foot orthoses (AFOs) just before she turned two. Based on a muscle biopsy, doctors believe she has Duchenne muscular dystrophy. However, D.N. has doubts about this diagnosis because this type of muscular dystrophy is rare in females, is not evident at birth and leads to elevated creatine phosphokinase (CPK) levels—Amanda's CPK levels are normal.

I read your letter out loud to my husband. When I got to the part where you said "I have a strong feeling that one of the readers of *Exceptional Parent* has seen a child like Amanda," my husband sarcastically replied, "No, we've never seen anything like that..."

Two of our three children have a connective tissue disorder called Ehlers-Danlos syndrome (EDS). Has anyone considered this syndrome as a diagnosis for Amanda?

EDS causes extreme joint laxity and dislocations in some children. Brynthea, the first of our two children to be diagnosed with EDS, was tested for the disorder after I told her pediatrician that she would pop her hips and shoulders in and out at will to gross out her sister and brother. She was slightly delayed with sitting and crawling.

Good luck to you. It must be terribly hard to search for a diagnosis. It's hard enough having one!

R.K., Pennsylvania

■ We saw our own experiences mirrored in the letter from Amanda's parents. Our son was born in May 1984 with low muscle tone, joint hypermobility and velvety skin. Like Amanda, he started walking after getting AFOs. Our doctors considered muscular dystrophy as a diagnosis, but he did not fit all the criteria. Finally, the genetics specialist decided to investigate a connective tissue disorder called Ehlers-Darlos syndrome (EDS). A tissue biopsy confirmed this diagnosis. There are about 15 different sub-types of this disorder. •

The Ehlers-Danlos National Foundation was established by Nancy Rogowski and her husband in 1985. This foundation is an enormous support for anyone who has EDS or knows someone who does. The foundation can refer Amanda's family to resources for diagnostic testing. If Amanda is diagnosed with EDS, they can put her family in touch with others in their area.

D.D. & M.D., Iowa

EDITOR'S NOTE: The Ehlers-Danlos National Foundation may be contacted at P.O. Box 1212, Southgate, MI 48195; (313) 282-0180, (313) 282-2793 (fax).



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# rathers voices

# **Crisis**

#### Poetry and photos by Galen Lowe

ake two aspirin and call me in the morning; life should be so simple. My ten-year-old son Brennen has a fever and is unable to swallow—swish and spit, swish and spit, over and over.

This is new, something different. I call the doctor's office.

The nurse's voice sounds measured, reluctant to squeeze yet another patient into an already overcrowded schedule. "Well, if he can't swallow, I guess you'd better bring him in." Brennen is listless in the car; he staggers like a drunk across the parking lot and into the doctor's office.

I never imagined how sick a child could be. I never imagined I would hear a doctor saying, "The next few minutes will be critical. If we don't work fast, your son may die."

The next few minutes have stretched out for three years. We've seen times of crisis, as well as times of peace. Brennen had fallen prey to an infection that made his epiglottis, the skin-sized flap that closes when we swallow, swell up to the size of his thumb. He could not breathe without a tube running down his throat into his lungs. His mouth taped shut around the tube, he could not speak. Nights were hard.

A sticky fluid began building up inside his lungs; a respirator was brought in to help him breathe. Scared, I wrote "Kites" at 2:08 in the morning while Brennen was lying awake in his hospital bed, exhausted, and trying to cough around his breathing tube.

Brennen spent two weeks in intensive care, recovering from that infection only to have his body's white blood cells rise up in rebellion against him. Leukemia—another year in and out of the hospital. Now, fortunately, chemotherapy, radiation, shots and a never-ending supply of pills have finally laid this beast to rest. Brennen is now six months out of treatment, and confident he'll never be back.

As parents of children affected by disability or disease, we face challenges that force us to reach deeply inside for resources we may not have known existed. For some, the challenge lasts a lifetime; for others, the experience plays itself out over a much shorter segment of time.

and Sierra.

These poems are expressions of what it was like to be with my son in the hospital while he was living with the

agony and frustration of cancer...

Brennen Lowe with sisters, Kelsey



#### **Apples**

If I have to go back to the hospital again to be with my son, I'll always take my knife

Because there is never anything sharp enough in the parents' kitchen to cut up the apples that frustrate several plastic knives before yielding finally to the blunt edge of a spatula I find behind the microwave.

When all I want is a slice of normal life like apples in my cereal for breakfast.

### Nighttime on the

We are the parents who wait unnerved

**Pediatric Floor** 

rocking and holding waiting and hoping our courage prevails

> our dreams reveal

a pearl in place of peril.

#### I Don't Feel

I don't feel like doing anything except the things I need to do to survive.

I eat, sleep, dance and look for comfort in the presence of friends I care for.

The rest of my world, the part composed of responsibilities, is piling up around me untouched

as mountains reaching toward heights
I vonder
If I shall
ever breach.



#### The Quilt

#### A Requiem

Whose hands will make the quilt
whose hands will lovingly stitch
the fabric, fold the cloth
color in details of the faces
long since gone, of our children
who died young, from cancer?

What field will lie covered
by great squares laid out
open to the mercy of a
fickle wind that may
at any moment crumble
our memories, as it has their lives?

Whose hearts will lie open in sorrow disbelief at the premature harvest of life whose hands thrust deep into pockets or held tight behind backs will hold tears of sorrow at the injustice of our loss.

This poem was written after viewing the AIDS quilt.



Despite his many tubes, Brennen plays plenty of Nintendo.

Fathers' Voices is a regular feature of Exceptional Parent magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum momoting fathers as significant, nurturing people in sildren's and families' lives.



Just about to leave the hospital, Brennen is already thinking about his next ballgame.

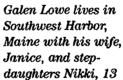
#### **Kites**

When it hurts, do you ever try to think of kites tied not to tubes but to strings?

And about how one of these strings, one slender thread of white against the blue, dips down from Above, lifting you and your hand up out of bed, calling you to run free to a place where leaping sideways

You can dance laughing in the shadow of their tails?

(Clockwise from left)
Kelsey and Galen Lowe,
Janice Done Lowe,
Brennen and Sierra Lowe
and Julia Conti.





and Julia, 12. Galen's children, Brennen, 13, Sierra, 7, and Kelsey, 15, live alternate weeks with Lowe and his former wife, Linden O'Ryan. Brennen's hobbies include soccer and competitive swimming as a member of the Mt. Desert Island YMCA swim team.

EDITOR'S NOTE: AS EXCEPTIONAL PARENT was going to presi, we learned that Brennan had suffered a relapse of leukemia. Doctors hope he will be able to undergo a hone marrow transplant in the coming months.

# Kole Models

# **Thomas Strax**

Learning to stand

Thomas E. Strax, M.D. is medical director of the JFK Johnson Rehabilitation Institute in Edison, New Jersey. He is also a professor and department chair at Robert Wood Johnson Medical School and serves on the board of directors for United Cerebral Palsy of New Jersey. Strax, 53, graduated from New York University School of Medicine in 1967. He has a 24-year-old son and 25-year-old daughter.

The following was adapted from a recent interview between Strax and Andrea Kamens, an intern at EXCEPTIONAL PARENT.

'm old enough to go back to a time when parents were overprotective and ashamed of children with disabilities. Children with disabilities did not attend school or play in the neighborhood. However, my parents had the radical idea that if I was going to exist in a hostile society, I should be integrated into that society as early as possible. My parents treated me like they treated my two able-bodied sisters—as a child who had to learn to become independent and not as one to be pitied or coddled.

I was born a mess. I was a breach delivery, with a prolonged stage 2, which means not enough oxygen reached my brain—a hallmark cause of cerebral palsy.

When I was growing up in Queens, New York in the 1940s, public schools did not admit "handicapped children." Although I don't know the details, my parents took the issue to court and I ended up at a public elementary school.

I was always around able-bodied children my own age. My mother started a Cub Scout den with neighborhood



Dr. Thomas Strax consults with attending physiatrist (rehabilitation specialist) Dr. Sara Cuccurulio at the JFK Johnson Rehabilitation Institute in New Jersey, 1994.

kids, and, when I was 11, sent me to a "normal" sleep-away camp.

At camp, my counselor set up sports so that the team that chose me was never at a disadvantage. In baseball, I had a substitute runner. If I got tired on a hike, a counselor carried me on his back.

#### Fitting in

During my first day at Bayside High School, we had to write our family history on little cards. Since I couldn't write that small, I asked the guy next to me for help. It turned out that he became a class leader. When we became friends, I became one of those fortunate ugly ducklings who got into the "in-crowd."

I couldn't always rely on luck. When it came to dating, I had to hold my own. Once, I asked the best looking girl in camp to a dance. She said yes. What I didn't know was that all the other guys were drawing straws to see who would get to ask her. I got beaten up, but I had a great time at the dance

Another girl I had dated asked me, after a good night kiss, "Can you have sex?"

I asked back, "Can you?"

#### Rules of life

Middle adolescence was a lonely time, because my friends had girlfriends and I did not. But, college was an equalizing experience.

Someone once asked my college roommate, "What do you do special for Tommy?" He said, "When Tommy falls down, I kick him." That may be facetious, but it's vital that children with disabilities learn the rules of life. Sometimes, that means letting them get hurt.

One reason it is hard for people with disabilities to get jobs is that becoming employable involves a tremendous number of social skills. If you haven't been able to grow socially with your peers, you can't make it as an adult.

To become an adult, you have to find your own identity. Able-bodied children do this by trying on different identities until they find one that fits. I did the same thing.

#### The family business

I always wanted to be a physician. There are 10 in my immediate family, most of whom went to New York University (NYU). My father, Selig Strax, is a famous surgeon; my uncle Phil won the Sloan Kettering Award for research in breast cancer—it's the family business.

It didn't always look as if I was going to make it though. When my parents first tried to get me into grade school, the superintendent said I had an IQ of 40 and should be institutionalized.

Physical issues were so pressing that, for a long time, no one knew where I was intellectually. My grades were C's and D's. In the early days, my report cards just marked me "present." Then, in high school, I grew into

physical maturity and began earning A's and B's.

.When I applied to medical schools. reactions varied. During one interview. I was told, "How dare you waste my time when there are ablebodied people who want to get in!"

My first rejection came from Albert Einstein College of Medicine in New York, However, soon after, I received a call from the dean. He wanted to know why someone with cerebral palsy felt he could handle medical school. I told him; two weeks later, I received my letter of admission.

In the end, however, I went to NYU, following in my family's footsteps. To my knowledge, I was the second person with cerebral palsy to formally practice medicine.

#### Thrust into activism

Since becoming a doctor, I have also become an activist. I had no choice. I was one of the first children with disabilities to be mainstreamed in the New York public schools. In college and medical school, I was the only person with a disability on campus. I became a symbol, a d people used me to decide whether or not to let others follow.

Sometimes, it makes me angry. It's easier to deal with a group as if they were homogeneous, but we're not. Each person should be evaluated as an individual and not by anyone else's success or failure.

In my field, a disability is sometimes seen as an advantage. Many patients believe someone who has a disability will be more empathetic about injury or illness.

However, I don't think I make a better physiatrist (a specialist in rehabilitation medicine) because I have a disability, any more than a woman makes the ideal gynecologist. You don't have to experience something to understand it, nor does experience guarantee empathy.

#### Not "handicapped"

In 1973, during a speech, I "defined" three words we often misuse"impairment." "disability" and "handicap." I later helped write these definitions into the Americans With Disabilities Act (ADA).

An "impairment" is something you don't have, such as full strength in your leg. A "disability" is someJohnson Rehabilitation Institute in New Jersey in 1985.

thing you can't do because of that impairment; you can't walk fast because of your weak leg.

A "handicap" has to do with functional need. If you are going to be CEO of a major corporation, walting slowly is not a handicap. If you're going to be a patrolman chasing down gangsters with your bad leg, then, you are handicapped.

In the 1970s, I was asked to appear in television commercials for the national United Cerebral Palsy Associations. I agreed, but demanded I be treated as a competent professional. I appeared as a doctor examining patients. It was the first major media commercial not to use the word "cripple" when describing someone with a physical disability.

#### Changing times

I've seen, and effected, a lot of changes in our society. I introduced reverse mainstreaming to JFK Medical Center's child care and pediatric rehabilitation programs so children with and without disabilities can learn and play together. I've helped students gain admission to exams and graduate programs by insisting they be judged on their individual merits. not their disabilities.

I hope I have gone from being "the only one" to being just the beginning. I am glad to see that today, many more parents are raising children the way mine did, to stand on their own. EP



Dr. Thomas Strax was named medical director of the JFK

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## familiar faces



Caitlin Hoel, 3, knows that riding her tractor in the front yard of her Ballwin, Missouri home is the perfect way to enjoy a sunny afternoon. Caitlin's mom. Tracv. remembers the day Caitlin, then eight months old, was diagnosed with Alcardi syndrome—"The doctor said she would never crawl or walk, and probably wouldn't live to her first birthday. She sure showed him, and us

This accomplished young squestrian is Jessica Lea Baider of Buffalo, New York: Jessica, 7, has hypometanosis of ito with developmental delays. She is included in a regular first grade class and enjoys school almost as inuch as horseback riding.





Four-year-old Tyler Nakonechy lives in Grand Forks, North Dakota with mom Mickie, dad Perry and little sister Brenna. Mickie says that Tyler, who has cerebral palsy, is "a little boy of few words but many smiles—the biggest of which are saved for his daddy!"



The Telkamp kids enjoy a wagon ride near their home in Hawthorne, California. Seated in the wagon are (from left) Alex, 4, and Christopher, 2. Standing next to the wagon is Alex's twin, Julie. Alex has hydrocephalus, cerebral palsy and cortical blindness; he enjoys school, wagon rides and being told how very handsome he is. Christopher, who has autism, is a big fan of Barney the dinosaur and cheese puffs.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, Exceptional Parent, 209 Harvard Street, Sulte 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and Identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

Michael Verdin, 3, prepares to follow his right shoe down the alide on his backyard jungle gym. Michael, who lives in Tules, Okiahoms, has tuber-ous scierosis.



397

# PHOTOGRAPHS BY DENNIS PAXENOS

## Saying it a Different Way

"Problem behaviors" may be a means of communication

by Judi Rosenstein and Jan Turner

A shley's parents had come to dread dinnertime. Almost every evening, the family's meal was interupted by Ashley's kicking. screaming or throwing of silverware. Her behavior made it impossible for the family to eat at their favorite restaurant or go to relatives' homes for holiday dinners. Her parents were desperate for a "solution" to these disruptive behaviors that held them captive in their own home.

Ashley, a friendly two-year-old girl, has difficulty using and understanding language. Like most children who cannot use language to tell others what they want, Ashley has found alternative methods of expression. Unfortunately, Ashley's "words" include throwing toys, hitting, scratching or having a "temper tantrum."

#### Scolding doesn't work

Although it is tempting to simply scold a child whenever an inappropriate behavior occurs, this approach has its problems.

Responding to a child's disruptive behaviors—even by yelling—often gives the child something he or she wants, like your attention.

This may encourage the child to repeat the behavior.

There are other reasons why verbal requests or reprimands are often unsuccessful in helping children with communication problems improve their behavior. First, children who have difficulty understanding language may not understand a parent's words. Secondly, because a child with communication problems has difficulty using 'anguage, what a parent perceives as "problem behavior" may be the child's primary means of expression. It is difficult to eliminate a negative behav-

ior if it is the child's only way to communicate a particular message.

#### What is the child "saying?"

Several steps are involved in determining the communication needs served by a negative behavior such as hitting, screaming or temper tantrums. Begin by identifying situations where the behavior most often occurs. Then, plan to watch for instances of the child using this behavior in these situations. While



Children with communciation problems often need to learn alternative methods of expressing themselves; Byron tends to cry and have trantrums. Speech-language pathologist Judy Rosenstein teaches Bryon to indicate he wants to blow more bubbles by signing "more." Byron's mother and siblings are also learning sign language.

watching, note what happened immediately before the behavior began and what happened immediately afterwards. See if you can figure out whether the child "got" something as a result of the behavior—like attention or a second helping of a favorite food. Getting something you want as a result of using a specific behavior is sometimes called "natural reinforcement."

Once you have determined what the child is communicating with the prob-

lem behavior, you can try to teach more "appropriate" ways to convey the same message. Socially-acceptable alternatives might include gestures, pointing to pictures, formal sign language or the use of specific words or sentences. Appropriate professionals, such as speech-language therapists, can help you choose the best alternative(s) for your child. Whatever alternative or alternatives are chosen, it is important to make sure the child has the ability to

use these methods, and that others can understand them. If possible, offering children multiple modes of expression usually increases their power to affect their world, and consequently, decreases behavior problems.

#### How does it work?

Let's see how this plan worked for Ashley and her family. Ashley's parents began by discussing the problem behavior with professionals who were already involved with their daughter—her teacher, a speech-language pathologist and a behavioral psychologist. As a team, they decided to focus on the problem behaviors of hitting, screaming and throwing things, because these behaviors always occurred together. Ashley's parents told the team

that these behaviors most often occurred at mealtimes. After observing Ashley's mealtime behavior over the course of a week, her parents noticed that Ashley's negative behaviors often occurred after she saw her brother eating one of her favorite foods. Ashley's "tantrums" often resulted in somebody giving her a second helping of that food. Her parents also noticed that Ashley exhibited similar behaviors at other times, when she wanted toys that were out of reach or an object

continued on page 22



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#### C() MMUNICATION



Timothy is learning how to follow directions. Today's lesson is "setting the table."

continued from page 21 someone else was using.

Ashley's parents decided that tantrums were her way of making requests. Other people had trouble understanding Ashley's unclear speech, but everyone responded quickly when she started hitting, screaming and throwing things. In a sense, Ashley's communication needs were satisfied with these behaviors.

Ashley needed to learn to make requests in a more socially-acceptable way. Because her speech was still unclear, the team decided to introduce pointing as a way of making requests. Her parents began this process by pairing the new way of asking for something (pointing) with the old way (tantruming). Whenever Ashley used a tantrum to make a request, her parents pointed to and named the object they thought she wanted.

By using words with pointing, Ashley's parents were trying to give her an example of the words she could use to make a request. Because Ashley rarely used words, or combined words in sentences, her parents used single words, such as "cookie" or "car." This language "model" was basic enough that Ashley could attempt to imitate it. And the pairing of pointing and speaking showed Ashley that both ways of requesting meant the same thing.

Next, Ashley's parents started helping her use the new way of making requests. If Ashley didn't try pointing before beginning her unacceptable behaviors, her parents moved her hand to help her point toward the object they thought she wanted. Then they named it and gave it to her. In this way, getting the object she wanted became a "natural reinforcement" for pointing.

At first, Ashley only pointed to objects when her parents prompted her to do so. Later, she began to use pointing without a prompt—though still not consistently. Once Ashley's parents were sure she understood this new way of making requests, they

began trying to ignore her tantrums. They accepted any socially-acceptable attempt at making a request, and "reinforced" these appropriate behaviors by giving her the object she wanted.

Gradually, Ashley learned that she could get what she wanted by pointing or trying to talk, but not by using tantrums.

More power through words
Increasing Ashley's vocabulary, both the
words she can understand (often called
"receptive vocabulary") and the words
she can use (often called "expressive
vocabulary"), also gives her more
options for communication. Over time,
she will begin to use the words her parents say when they encourage her to
point. She will learn that words are
more specific than pointing, and, there-

fore, more powerful—especially with people who don't "read" her non-verbal signals as well as her family.

#### Positive changes

As Ashley has learned more appropriate ways to communicate her needs, her parents and teachers have seen a dramatic decrease in negative behaviors. However, because communication is still difficult for Ashley, she sometimes reverts to using disruptive behaviors when she is tired or under stress. At these times, her parents try their best to avoid "rewarding" these negative behaviors by giving her what she wants. Instead, they encourage her to try using a gesture or a word. **EP** 

Judi Rosenstein, M.S., CCC-SLP is a speech-language pathologist at Kennedy Krieger Institute in Baltimore, Maryland. She evaluates and treats children and adolescents with communication disorders, and behavior problems and communication disorders.

Jan Turner, Ph.D., CCC-SLP is director of the Speech and Language
Department at Kennedy Krieger
Institute. She is particularly interested in language disorders associated with learning disabilities, and with the difficulties some children have in storytelling or conversational interaction.

#### **Communication Problems**

Communication problems, like behavior problems, can occur alone or along with movement, learning or emotional problems. In fact, behavior problems may be the result of undiagnosed or untreated communication problems. Children of any age may have communication problems or behavior problems, or both, although communication disorders more often are diagnosed in younger children. Communication difficulties that begin at an early age may persist as a child grows older, or a communication problem may become evident for the first time as older children face increasing communication demands with peers, at home or at school.

Many families may find that the techniques presented in this article will be helpful in resolving their children's behavior problems. Some families will be able to apply these principles on their own, while others may find it more beneficial to work with professionals. Experienced "outsiders" may have an easier time identifying problem behaviors and the situations that trigger them. In any case, it will be easier for a child to learn new communication modes if all adults involved with the child on a cular basis—including teachers and other professionals—are involved in the effort to teach and reinforce these methods.

Children whose actions are severe enough to cause injury to themselves or others need immediate professional help. Parents who are not sure about the seriousness of a child's behaviors should discuss the behaviors with medical or educational professionals.

Children who may need more elaborate or electronic communication systems can be referred to appropriate specialists for these services. (See "Getting Started with Augmentative Communication," page 34.)

—J.R. & J.T.



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# Turn-taking: A Giant Step to Communicating

by James McDonald

hildren learn to communicate by taking an active part in interactions, not by simply listening to adults, or being "taught" words.

Staying in conversations is so natural for us that we don't think about it, but children with developmental delays often need a great deal of practice taking turns with movements and sounds, even before they start to talk.

Most babies learn reciprocal turntaking (back-and-forth interaction between partners who respond to what the other does and says) through natural interactions with adults exchanging funny faces and sounds, waving "bye-bye" and playing "peek-aboo." Turn-taking soon becomes a lifelong habit.

But turn-taking can be difficult and discouraging for some children—especially if adults take most of the turns.

Adults often find it difficult to wait for slower children to respond, but waiting is one of the most important ways to help children learn to communicate.

## What children learn from turn-taking

Here are five important things a child can learn by taking turns:

- How to initiate interactions. Some adults have a tendency to start and to take over activities and conversations; this can cause children to become passive observers or followers. If children are encouraged to take the lead frequently, they will learn to choose their own activities and topics.
- How to imitate others. Children learn a lot by imitating, or attempting to imitate, what other people do. When we engage in back-and-forth interactions with a child, using

motions, sounds or words, the child feels motivated to imitate.

- How to respond creatively. Although learning to imitate is important; children will enjoy interactions more if they feel free to respond in their own ways, without fear of failure or criticism. A child's actual responses are not nearly as important as the fact that he is getting practice taking turns and learning to prefer being with people more than with things.
- How to use actions in useful and meaningful ways. Before they learn to talk, children need a lot of practice trying out different actions and sounds. Turn-taking interactions give children opportunities to try out new actions and sounds.
- How to keep interactions going. Often, children with developmental

#### **Becoming Andrew's Playmate**

Until he was three years old, Andrew was an isolated and physically defensive child with autistic characteristics. He communicated only with screams. I hoped he would learn better communication skills once he got to school.

During a chaotic first year of preschool, we were able to find ways to help Andrew stay calm. However, he still didn't interact with other people, and his communication skills didn't improve

Then I learned how important it was to play with Andrew in ways he could play. I wanted Andrew to learn to take turns, and I started by imitating his actions. Resistant at first, Andrew eventually began imitating me and enjoying our contacts.

I had never thought about all the little things Andrew did; I just wanted him to talk. But I was starting to realize that Andrew's every sound and movement could be an important step in learning to communicate.

We took turns making funny sounds and body movements. When watching TV, we'd point and squeal at the Muppets and other "friends." In the kitchen, we'd take turns getting a drink or putting away silverware.

Once I realized that Andrew would not learn to communicate unless he interacted more with people, I started trying to

keep him for "one more turn" when he started to leave me. He began staying longer; in fact, he started coming to me to initiate our play.

After a lot of work, Andrew got the idea. He chose to be with people more often. After being alone for so long, he was finally interacting.

Now, Andrew is so much more fun to

be with. Andrew, now four and a half, is just starting to talk. But he didn't start talking until I forgot about teaching him to talk, and just started playing back and forth at every opportunity. I had to become his playmate, not his teacher or therapist. I would advise other parents to do the same—have fun, and let your child teach you how to slow down and appreciate things for what they are.

—Pam Rodawalt Columbus, Ohio

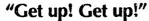
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delays interact only briefly before being distracted by another activity or object. However, to become real communicators, children need to learn how to stay in interactions. As a first step toward communication, learning to enjoy people is more important than learning to make sounds and words correctly. The best way to help children learn this is to show them that playing and interacting with us is fun, not work! When adults become partners-rather than "directors" or "instructors"—children learn that their actions are important and often find ways to keep interactions going.

#### Turn-taking strategies

Any action or sound a child makes can become an interaction or communication. By responding to a child's seemingly meaningless behaviors, we can



Since I've learned how to play and talk with my seven-year-old grandson, Marcus, he's beginning to communicate with me much more. Marcus, who I am raising, has Down syndrome and is just starting to talk in words we can really understand, It's so exciting!

I began interacting more with Marcus after I learned to "match and wait." a technique in which I say something, then wait for Marcus to imitate me before I do anything else. He usually repeats what I say, but he's also starting to initiate more on his own. Last week, he came into my bedroom and said,



Barbara Cook with grandson Marcus Moore, 7.

"Get up! Get up!" This was the first time he had ever done this, so, of course, I got up. I wish I would have learned about matching and turn-taking when Marcus was younger; I think he would be doing much more now. Now, I "match and wait" in almost everything we do together.

Marcus likes to help me wash dishes. When I say things like "dirty dishes," "wash,

wash," "rinse cup" and "ali clean now," he imitates me.

I also imitate Marcus' actions a lot when we play together. He still plays like a younger child, so that's what I do. He likes to throw stuffed animals at me in a little back-and-forth game, so I throw them back and say "good throw," "duck down," "missed" and "cheating!"

I've learned that any game can turn into a conversation if you just become part of your child's world.

--Barbara Cook Bellefontaine, Ohio



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#### **Making Turn-taking Fun**

Finding ways to take turns is fun and easy, once you get in the habit. I've learned three things about turn-taking: first, watch what your child is doing and become part of it; second, keep the interaction going for awhile; and third, make it fun!

This morning at breakfast, my son, Mark, a five-year-old with

Down syndrome, was pretending to read the back of the Cap'n Crunch box. I peeked around the box and said "Hi!"

He poked his head out and said, "Hi!" back. The game had started. We made funny faces, growls and roars back and forth with each other as he looked at me from one side of the box, then the other.

Here's another game we've played with words. One day, Mark called me Barbara. This was the first time he had done that, and it was a real surprise. I looked at him—just a little sternly—and said, "Don't call me 'Barbara.' Call me 'mama."

He repeated "mama," then said "Barbara" again.

Then I knew how to make a turn-taking game of it. I changed my words a little and said, "Don't call me 'Barbara!' Call me 'mother dear."

Well, of course, he repeated "mother dear," then said "Barbara" again, this time with a big grin.

What a game! We went through "sweet mama," "pretty mommy," "skinny mom," "smart mama" and just about everything else I could think of. He loved it! Even after we ended the game, he would sneak up behind me and

say "Barbara," just to start it over again.
We don't play this game much anymore and I miss it. But all the funny faces, silly sounds and word games have served an important purpose for Mark's development—our days are now one long conversation.

-Barbara Mitchell West Liberty, Ohio



continued from page 25

make these behaviors interactive. The more we enter our child's world and wait for the child to participate, the more likely it is that his actions will become social and meaningful.

Whether your child uses actions and sounds to communicate or is already

beginning to talk in sentences, you can help the child take turns by making a habit of the following strategies:

• Keep your child interacting with you. Don't wait for play times to teach your child about turn-taking. Interactions will be more enjoyable for both of you when they occur naturally and spontaneously throughout the day. Try to have many little back-and-forth exchanges with your child during all your normal activities. The more practice your child gets and the longer he stays interacting, the more he will learn about communicating. Try to keep your child interacting with you just a little longer each time. You can do this by making interactions fun.

• Balance turns. This means you and your child each get the same number of turns. Give your child your complete attention and the time he or she needs to do something—this will help the child feel successful and self-confident.

Try to avoid question-and-answer routines in which you simply ask a child to label pictures or objects—"What is this?" "doll;" "What is this?" "bunny." Boring routines won't help a child learn creative, spontaneous turntaking. Instead, add variety to your turn-taking by using different actions, sounds and words that your child can do and say.

• Act and communicate like your child. The more you "match" your child's actions and sounds, the more he will learn from you. If your child doesn't speak yet, you can copy his or her movements, sounds or gestures. If your child is beginning to talk, use the words he or she knows how to say. When we act and communicate like our children, they stay in the interaction longer. That gives us the chance to show them the

continued on page 28

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#### **Seven Years of Turn-taking**

Our daughter Laura spent the first year and a half of her life in the hospital after being born with multiple complications. When we brought her home, she was on a feeding pump. She did not speak and had very little physical movement, but she always appeared to be observing the world around her.

When she was about three, Laura was able to begin outside therapy and preschool—always accompanied by a nurse or me. Finally, our family began to think about the future. A friend

referred us to lim MacDonald's clinic.

We arrived at Jim's office—Laura, Grandma, me, a feeding pump, a suction machine and oxygen. While we waited for Jim, I talked to Laura, shaking rattles in her face, trying to "stimulate" her. I wanted to make a good first impression.

As Jim walked into the room he said, "Would you please

quit talking." I was offended and shocked.

But then I watched as he began interacting with Laura on the most basic level. If Laura moved her arm, he moved his arm in exactly the same way. If she glanced at something in the room, he followed her gaze, using single words to comment on what they were looking at. Laura never took her eyes off of him.

Over the following months, Jim taught us about turn-taking, matching and waiting. This involved adjustments for the whole family. Not only were we dealing with a child who had multiple disabilities, we were also learning to communicate

with her in new ways.

It was hard for me to learn how to play with my daughter. My definition of play was "do, do, do; teach, teach, teach; stimulate, stimulate, stimulate." But I was doing all the "doing, teaching and stimulating," I was trying to teach Laura things like colors, and she was just sitting there. Laura was not communicating with me, and I was frustrated and discouraged.

It took a long time for me to reach Laura's communication level and feel good about it. However, once I did, I began getting responses from Laura. She started to imitate me, and her eyes glistened with delight while we played. She began making very basic sounds, which I would repeat. Eventually, I started adding syllables. Laura was starting to communicate with us, and we understood her.

I also learned the importance of waiting. In my earlier interaction style, if Laura didn't respond quickly, I would either tell her the correct response or move on. By waiting, I began allowing

Laura the time she needed to respond.

Laura, now 10, is in a regular classroom with supports. She has a delightful sense of humor, independence and faimess, and she *always* has something to say. Laura still struggles with finding the words, but if we wait, she always comes through.

—Jan Daily Worthington, Ohio

Laura Daily (right) enjoys playing with best friend Mariene Moore.



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"It's your turn, David." "What's the matter?" "Do you want pizza or a hamburger for lunch?"

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#### C() MMUNICATION

continued from page 26

next step they need for their develop-

- · Wait, signal and expect. Children need to participate in order to learn-it is not enough to listen to us talk. If an adult does not wait, the child misses his or her turn. Use a look of genuine anticipation to show your child that you expect something. If the child doesn't know what to do, you can point or physically help the child to take a turn. However, often, just waiting will elicit much more from a child.
- Imitate and animate. If you feel that you don't know how to play and communicate with your child, imitating the child's actions and sounds is a good way to start a turn-taking interaction.

Practice taking turns with no pressure to teach any particular skills. A child will stay with an interaction longer and do more when you make no demands other than keeping him there. Keep track of just two things-how long he stays and new things he does. Make those your rewards!

When adults say, "I can't think of what to do with my child," we reply, "First look at what he is doing. Then follow his lead, and then do something that keeps him doing his things with you." EP

James McDonald, Ph.D, C.C.C., is associate professor of speech and hearing science and director of the Parent-Child Communication Program at the Nissonger Center, both at The Ohio State University in Columbus, Ohio. The authors of the stories accompanying this article are participants in Dr. McDonald's program at the Nissonger

Dr. McDonald is the author of BECOMING PARTNERS WITH CHILDREN (Riverside Press, 1989) and is the editor of Communicating Partners, a quarterly newsletter for parents of children developing language. (Subscriptions are \$15 a year; Communicating PARTNERS, P.O. Box 141306, Columbus, OH 43214.) This article was adapted from the Summer 1994 issue.



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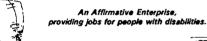


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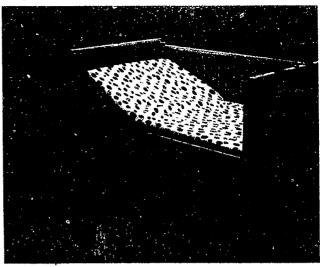


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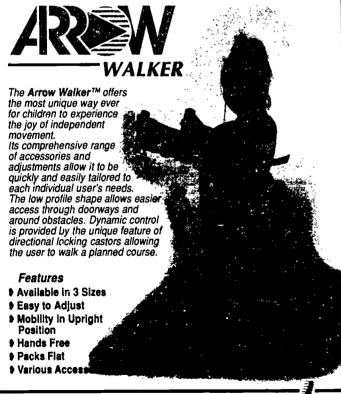


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## **Hearing Impairment & Hearing Aids**

by Joseph P. Pillion

I rom birth to age five, children are on the "fast track" for acquiring speech and language. As infants and young children build communication skills, they also build stronger and more meaningful relationships with their families. Surrounded by examples of speech used to refer to everyday objects and activities, children learn to produce the same speech sounds to express themselves.

Learning to talk and understand others, then, depends heavily on the ability to hear. For young children whose speech and language development has not kept up with their peers, hearing testing is especially critical. If a child with a hearing impairment receives help and good auditory input at an early age, he or she will have a better chance of learning to use speech and language successfully.

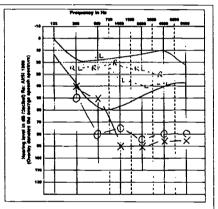
#### **Evaluating hearing**

A child's auditory function should be evaluated by an audiologist, a professional who measures hearing and can fit people with different equipment to enhance their hearing. Infants and children from six months to two years of age are tested with a technique known as visual reinforcement audiometry. In this test, the child is exposed to animated toys that appear in a window as sounds are presented through a speaker or earphones. The child's hearing can be lested once the child has learned to anticipate the toys' appearance by turning toward the window whenever he or shes hears a sound. Older children may be asked to place pegs in a pegboard or blocks in a bucket when sounds are heard.

Special test procedures can be used with infants or older children who are unable to make voluntary responses to sound. For example, auditory evoked potentials (AEPs) use a computer to measure the brain's response to sound. AEPs—which require that the child be asleep or under light sedation—use electrodes taped to the scalp to mea-

sure the brain's electrical activity while sounds are presented.

One component of an AEP evaluation is the auditory brainstem response (ABR) or brainstem auditory evoked response (BAER). Audiologists can use ABRs to assess the hearing of even newborn infants. Any infant at risk for hearing impairments—those with a family history of hearing impairment, very low birth weight, cleft palate and/or certain developmental disabilities—should be tested.



This is the audiogram of a child with a bilateral, moderate-to-severe hearing loss. Frequency of the sounds (pitch) appears across the top of the graph; intensity (loudness) appear along the side. The shaded region of the graph shows the typical frequency and intensity of conversational speech. The audiologist has plotted this child's responses to sound with red circles (right ear) and blue X's (left ear).

Without hearing aids, this child hears very few speech sounds. However, with hearing aids—shown as "R" and "L" (for right and left ears)—the child can hear most sounds in a typical conversation.

#### Types of hearing loss

Each sound can be characterized by its pitch, or "frequency" (measured in cycles per second—Hertz, abbreviated as "Hz") and by its loudness, or "intensity" (measured in decibels, abbreviated as "dB"). Most speech sounds fall between 250–4000 Hz. Conversational speech is usually at about 60 dB in intensity.

During a hearing evaluation, the audiologist plots the quietest sound that an individual can hear at each frequency on a graph called an "audiogram." As viewed on an audiogram, hearing losses may have different shapes. One child may only have trouble hearing high frequency sounds, but hear everything else normally. Another may miss only low-intensity or quiet sounds, but hear fairly evenly across all frequencies. These two listeners would hear the same speech differently. The first child might not be able to hear specific high-frequency speech sounds like "f" and "s," while the second may be able to hear all the speech sounds-but only if they are loud enough. Individuals can have either type of hearing loss, or a combination of the two.

#### **Amplification**

Boosting hearing level is called "amplification." When a child's hearing is not within a normal range, parents and professionals work together to decide if amplification will improve the child's ability to understand and use speech. An audiologist will try to provide a hearing aid that will allow the child to comfortably hear the full range of speech frequencies and intensities.

Sensorineural hearing impairment, which involves damage to the inner ear or the auditory nerve, may have an adverse effect on a child's perception of loudness. A child with this type of hearing loss may perceive barely detectable sounds as uncomfortably loud. The audiologist will try to solve this problem by adjusting the aid to control the maximum possible sound produced by the tiny speaker in the hearing aid-also known as the aid's "output." Hearing aids also include circuits that permit audiologists to adjust the output to provide more amplification in the frequency region where the child has the greatert amount of hearing loss.

A variety of amplification devices ar available. However, audiologists generally prefer behind-the-ear hearing aids

continued on page 32

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continued from page 30

for young children because they can be fine-tuned more easily as additional information about the child's hearing loss becomes available, or if a child's hearing changes over time. Because infants and toddlers grow so fast, in-the-ear and canal-type hearing aids are not typically used—as a child grew, the instruments would need constant re-sizing. With behind-the-ear hearing aids, only the earmold needs to be replaced as a child grows.

Assistive listening devices may also be available in public places. These include FM systems (like small radios) and infrared listening systems, which use the same kind of signal used in TV/VCR remote controls. Designed to overcome the effects of background noise, these devices—common in theaters, churches and schools—transmit a speaker's voice directly to a listener's headphone.

Because of noise levels and bad acoustics in many classrooms, back-



In a visual reinforcement audiometry test, children may be asked to place pegs in a pegboard whenever a sound is heard.

ground noise can be a big problem in school. Acoustic ceiling tiles and wall-towall carpeting can improve acoustics dramatically. If necessary for a child, these classroom modifications, as well as classroom use of an assistive listening device, should be included on the child's IEP.

#### Hearing aid maintenance

Hearing aids worn by an active toddler are subjected to considerable wear and tear. Because a hearing aid is worn on the body, moisture may affect its delicate electronic circuitry. Hearing aid dehumidifier kits help prevent this type of damage.

It is important to monitor a child's hearing aid(s) on an ongoing basis to ensure optimal functioning. This includes daily battery checks and listening checks using a hearing aid stethoscope that can be purchased from an audiologist. Every three months, have the audiologist take standardized measurements of hearing aid performance. Most hearing aid manufacturers provide a one-year insurance plan for loss or damage. Extended policies can be purchased through the manufacturer or a third-party insurance provider.



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Limitations of hearing aids

Parents and professionals should be aware of the limitations of hearing aids. In addition to speech, hearing aids amplify other sounds, such as environmental noise. When amplification is sufficient to amplify speech, "background noise" may interfere and be bothersome to the hearing aid user.

Some children may have such severe hearing impairments that they are able to receive only limited benefit from hearing aids. In such cases, hearing aid use may only provide a child with awareness of environmental sounds like car horns and smoke detectors, or access to certain features of speech, such as changes in loudness or pitch, which may add clues to lip reading.

If a hearing aid is not sufficient to allow a child to develop speech and language, other communication options—such as sign language-should be explored. Cochlear implant surgery is another

Behind-the-ear hearing aids are the most common form of amplification prescribed for toddlers and younger children. As the child grows, only the earmold will need replacement.

option that could be discussed with an otolaryngologist (an ear, nose and throat doctor). Cochlear implants have been very controversial within the deaf community. Although some profoundly deaf individuals have become able to discriminate conversational level speech remarkably well after receiving cochlear implants, others receive far less benefit.

Providing hearing aids to a young child is a critical first step. But children with hearing impairments also need early intervention-including language stimulation-during their primary languagelearning years. Auditory training can help new hearing aid users learn to pay attention to auditory signals, to recognize dif-



ferences between auditory signals and to associate meaning with sounds.

For more information, or referral to resources in your area, contact the American Speech-Language-Hearing Association, 10801 Rockville Pike, Rockville, MD 20852, (800) 638-8255 (V/TTY), (301) 897-5700 (V/TTY), (301) 571-0457 (fax).

Joseph P. Pillion, Ph.D., CCC-A is a senior audiologist at Kennedy Krieger Institute in Baltimore, Maryland. He has been with the institute for eight years and specializes in audiological management of children with brain disorders.



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# Getting Started with Augmentative Communication

by Naomi Angoff Chedd

"You're hungry? You want something from the cabinet...you want a cookie...a chocoate cookie? No. A graham cracker? No. Hmmm...a granola bar? Yes!" I breathe a sigh of relief; I figured it out fairly quickly this time.

y conversations with my four-year-old daughter, Kinsey, who has cerebral palsy and is not able to talk, often proceed along these lines. Using a combination of pointing, facial expressions, vocalizations, some simple signing that others would be hard-pressed to understand and my knowledge of her preferences, she can tell me what she wants. Most of the time I understand her, but it can be a struggle.

Is this the only way for us to communicate? Wouldn't it be more effective and satisfying if Kinsey could tell me right off the bat, "Mom, I want a granola bar. And how about some milk to go with it?" I often feel frustrated and impatient, and Kinsey obviously does too; she has a lot to say and only limited means of expressing herself. For Kinsey and many children like her, augmentative communication (AC) is a solution—possibly the only solution.

#### Defining augmentative communication

"AC always involves a voice synthesizer," one parent told me. "Don't you need to be able to use a computer?" asked another.

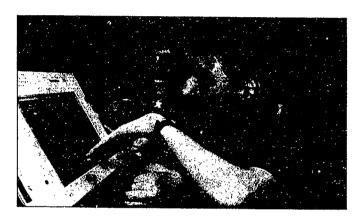
"I thought it referred to those picture boards kids in wheel-chairs use," responded a third.

AC is all of these things and more. It involves everything—pictures, sign language, computers, voice output devices, letter boards—that supplements or replaces speech.

Although many children will move from non-electronic communication devices to computers, most will use a combination of AC methods. A child may use a computer and voice output device in school, but use a picture notebook, vocalizing and/or signing at home.

No one way fits every situation and every child. The challenge is finding the right combination of solutions to provide *your* child with the fastest, most effective means of attaining his or her goals. And no matter what features a system has, remember that the only good communication system is one your child will use.

Although experts have varying opinions on how and when to design an AC system, they *all* agree on one thing—using an augmentative system will not inhibit speech production. Howard Shane, of the Communication Enhancement Center at Boston Children's Hospital, says AC often leads to improved speech—"It takes the pressure



Working with Edith Thayer, speech and language clinician for the Vineland School District in Vineland, New Jersey, William Troolin learned to communicate using his DynaVox within a few days. William, 16, has spastic quadriplegia, which limits his speech and mover..ent. Photo courtesy Sentient Systems Technology.

off kids. They can relax, and speech may come more easily." Shane added that for some children, "learning occurs using a visual modality, so picture systems can actually speed up speech and language acquisition." Also, success with other modes of communication motivates the child to experiment with all available means.

#### Low-tech options

Preschoolers often begin AC use with situation-specific picture or symbol boards illustrating activities, chores, foods, toys, emotions, friends and family. These help a child get used to making choices, expressing feelings and telling stories.

Large vocabulary picture books are divided into various sections and contain categories such as people, places, action words, leisure activities, movies and toys. Professionals should design a communication book, but parents and teachers can participate in the process.

#### Electronic devices

It would be impossible to describe every one of the wide range of electronic products, but they include:

- Small, hand-held keypads, with various options including screen displays, printout and voice output (requires direct selection, meaning the child selects options with a single finger);
- Hand-held picture display devices with voice output (also requires direct selection);
- Programmable keyboards of various sizes, with or without



411

voice output (can be used with direct selection, single switch use or scanning;

- Electronic picture communication books that fit into three ring binders and have voice output devices; and
- User-programmable devices (using direct selection or scanning), some of which include an auditory scanning function for users with visual impairments.

Home computers can be used as AC devices, and may be adapted to provide many selection options. These include touch screens, expanded keyboards and overlays requiring a lighter, less precise touch.

Pointing and typing aids, such as headsticks, mouthsticks, handsplints and optical lightbeam devices are also available.

#### The right system

Integrating an appropriate communication system into every-day life can be one of the major problems for children and parents. In my house, for example, we have 20 minutes to get breakfast ready, snacks made and two kids off to school. Selecting breakfast choices from a picture book would certainly help my daughter improve her symbolic communication skills, but sometimes it's easier to ask a question and get a nod of the head in response.

Jude O'Hara learned new things about her six-year-old son Stephen, who has cerebral palsy, after he started using a communication book. For example, the communication book,

which contains alphabet and number pages, gave Stephen his first chance to demonstrate his spelling and math skills. Steven's family is now exploring ways for him to access a computer system, which he will need for writing, homework assignments and conversing with friends.

Linda Freeman, the mother of Alexander, a sevenyear-old with cerebral palsy says therapists, AC experts, computer programmers and hardware designers have been working on developing a communication system for Alexander since he was two. "Alexander actually has one, but it's so difficult and time-consuming to use and has so many bugs that nobody wants to go near it. It frustrates him and everybody else," Linda says. "And it wasn't for lack of trying. Our team was creative,

continued on page 38



Alexander Freeman, 7, spells words using an Intellikeys keyboard and pointing device that was designed and constructed by a family friend.

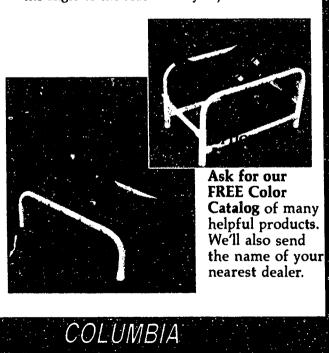
Occupational therapist Carrie Larson helps Alexander maintain his balance by holding his right hand down on the desk.



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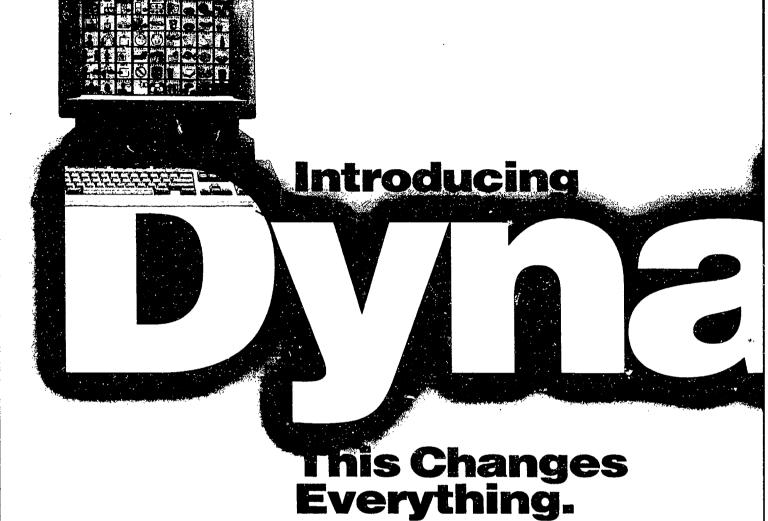
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## COMMUNICATION

continued from page 35

hard-working and committed to providing Alexander with a system he could happily use. But after spending all that time and money, we're starting again from square one."

Unfortunately, the Freemans' experience is not uncommon. One of the major problems they faced was that when Alexander's system was first beginning to take shape five years ago, the technology was fairly new and there were a lot of hardware and software problems. But whenever technology is central to a system's success, keeping up with the latest and best products and techniques will always be a challenge.

How to get started

• Determine if your child is a candidate for augmentative communication. AC can be used by anyone whose speech cannot meet their communication needs. Even if a child's family understands his or her speech, AC can provide a means for the child to interact with friends, teachers and other important people.

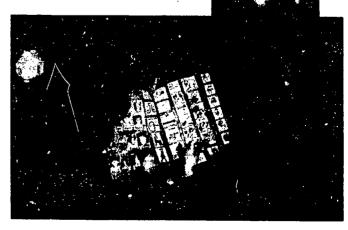
 Set specific and realistic goals. For a preschooler, making activity choices and friendships might be the best use of AC; an academically competitive fifth-grader might need a system that allows for quick response in class and provides a means of talking on the phone.

• Integrate pictures into everyday conversations with your child. This doesn't mean using a picture to communicate every noun, verb or adjective. But if you're going to McDonald's, for example, hold up a ketchup packet with the McDonald's logo. If you're going to see Grandma, point to a picture of Grandma. Says one AC specialist, "You can't talk to a non-verbal child using only words and then expect him to respond using only pictures. You need to model what you want

• Find an experienced AC specialist or clinic. Ask for advice from your speech pathologist, occupa-

your child to do."

In her preschool classroom, four-yearold Kinsey Chedd (right) uses a vocabulary picture book to communicate with teachers and classmates.



tional therapist (OT), physical therapist and other parents. Try to work with clinicians that are in it for the long haul; you'll need them.

- Get good language, vision, hearing and OT evaluations.

  Clinicians, especially OTs, can often provide valuable advice on positioning, system access and maximizing hand and eye use.

  Be sure they are involved from the beginning.
- Become an informed consumer. Product descriptions often
  make communication devices sound miraculous. Before purchasing anything, be sure you know how it works and what it
  can do. Talk to users and observe a variety of systems in action.
  Many manufacturers run seminars and workshops at trade
  shows. Most offer rentals as an alternative to purchase and
  some may let you borrow devices to try them out.
- Ask for help and cooperation from the school. Find someone with experience in designing AC systems or ask for outside consultation. "It is often the classroom aide who is the critical link and makes the difference between success and failure with an augmentative system," Shane says. "This is the person who knows your child the best and has the strongest commitment, but is the lowest paid and has the least training. I would like to see that change."

When I explained my daughter's capabilities and needs to a number of experts in the field, I received a variety of perspectives and information. I

asked when I should begin to get more aggressive with AC, and perhans the most useful ach ace came in the form of a question—"She's already four? What are you waiting for?" **EP** 



Naomi Angoff Chedd lives in Brookline,

Massachusetts with her husband, Graham, a filmmaker and television producer, and children, Harry, 5, and Kinsey, 4. Naomi is a freelance writer and graduate student in counseling psychology. She writes a regular parent column in the NDT Nework, a newsletter for therapists, published by the Neuro-Developmental Association, and is a new member of EXCEPTIONAL PARENT'S editorial staff.



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# FACILITATED COMMUNICATION: What Parents Should Know

by Karen Levine and Robert Wharton

ommunication—the ability to express one's thoughts, ideas and wishes to another person—is a vital component of life. However, when a developmental difference, such as language delay, motor impairment, developmental delay or autism, interferes with communication, a child needs extra help.

There are many approaches to enhancing a child's communication skills. Some children can benefit from speech therapy; others may learn to use gestures, signs or augmen-

tative communication systems. In the last five years, facilitated communication has received publicity as a possible breakthrough in communication.

#### What is facilitated communication?

A six-year-old boy with autism sits in his classroom next to a teacher. Until recently, the boy was considered developmentally delayed. He cannot say any words but seems to understand a few spoken phrases. In front of the boy and his

continued on page 42

#### An FC Nightmare

My husband and I were introduced to FC by a police detective, who told us our 13-year-old son son, Josh, had made allegations of sexual abuse against a family member. The detective gave us typed transcripts our scn was supposed to have produced at school when "facilitated" by his teacher. We had no idea Josh's teachers were using FC with Josh, who has moderate mental retardation.

We took Josh for a physical. We felt somewhat reassured when the doctor reported no physical signs of sexual molestation. But that reassurance was soon to evaporate.

I asked Josh's teachers and therapists how he could communicate like this. "He can talk," I said, "but he cannot read, write or spell." They said they could not explain it, but that FC was a miraculous new "thing" that unlocked hidden intelligence.

Although we were doubtful, we trusted these professionals. And we wanted to believe our son was intelligent enough to have taught himself to read, write and spell. We went along with their recommendation that Josh should continue using FC.

As months passed, it continued to be facilitated that Josh was being abused, was not protected by his family, or wanted to leave home to be safe. At one point, the police were called in to investigate claims he was making "plots and ploys to murder" his family.

I allowed the police to question Josh because they agreed to provide me with a videotape of the interview. It was heartrending to watch 43 minutes of Josh struggling with the facilitator, using spoken language to repeatedly say, "Can I stop now? Can I go back to the room? No, no, no! I don't want to do this." He repeatedly yanked his hand away from hers, turned the typewriter off and looked around the room while she "facilitated," concentrating intently on the keyboard. When an officer-suggested that our son might want to stop, the facilitator repeated the FC lore—what he says isn't valid; just pay attention to what is typed. The investigation continued.

A few weeks later, Josh's grandfather was accused of sexual abuse. My involvement was implied by a facilitated statement about "the ploy by my mother to appear normal."

We were distraught. If our son had been abused by anyone, we certainly wanted to know, but none of this made sense. Josh had never spoken about anything remotely resembling sexual molestation. Yet his teacher claimed this communication was coming from him.

A final "facilitated" police interview resulted in a typed sheet describing specific graphic sex acts involving me. I was hysterical after reading the accusations. School personnel then said they were

convinced that, although these were his words, Josh was lying. The detective in charge decided not to file any charges.

Despite that decision, I cried for weeks. I was terrified my child would be taken away from me, or that I might be arrested or forced to leave my home. I couldn't understand how the sweet, funny, talkative child I loved could have done this. Or why.



Josh Johnson and his sister, Samantha.

Then I discovered he didn't do it. We experimented with our own electric typewriter. I had believed Josh's hand could not be pushed to keys he didn't want to press, but I soon discovered that, holding his hand, I could speil whatever I wanted. If I looked away from the keyboard, the words turned to gibberish.

At our insistence, the school stopped using FC with Josh. His recovery from FC began the day he entered a new classroom. After months of having his spoken language ignored, he was finally being valued for himself again.

Some people call FC an inexpensive intervention. In fact, FC has enormous costs. We spent our life savings defending ourselves against false accusations. And we're not the only victims. FC has destroyed families, cost jobs, placed children and adults in homes with strangers ill-equipped to handle their needs, and undermined the credibility of professionals—who, despite the best of intentions—insist on ignoring the results of objective, scientific research.

---Cecilia Johnson Georgia

Johnson, along with other parents, has formed a support group for families who feel they have been hurt by FC. The group provides information, copies of scientific research, articles, and videos examining FC. For more information, call (404) 973-4045.

This piece was adapted from THE IARET NEWSLETTER (Summer/Fall 1994). For more information, see "From Someone Who's Been There and Back," page 51.



417

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Piagetian Tasks. (2nd Ed.) '81, 136 pp., 57 il., 2

#### C() MMUNICATION

continued from page 40

teacher is a piece of cardboard with the letters of the alphabet written on it. The teacher holds her hand gently around the child's hand; together they point to letters while the teacher says the letters and words aloud—"I... W-A-N-T... want... I want... S-T-R-A-W-B-E-R-R-Y... I-C-E-C-R-E-A-M... I want strawberry ice cream."

"Oh, you'll get it at lunch!" the teacher answers.

This technique of hand-over-hand spelling out of words is called facilitated communication (FC).

Australian educator Rosemary Crossley developed FC to help a woman with cerebral palsy communicate. Crossley began by using a hand-over-hand approach to help the woman, who had severe motor problems, indicate preferences by pointing to pictures. Crossley later expanded this technique to include the use of an alphabet board.

A few years later, Crossley began using FC with other students, including children and adults with autism and/or mental retardation. Although many of these individuals had not shown any previous evidence of verbal skills or literacy, through FC, they were reported to produce highly sophisicated communication.

In 1990, Douglas Biklen, a professor at Syracuse University in Syracuse, New York, observed Crossley and her students in Australia. He began writing about FC and teaching its use in this country.

#### Why is FC controversial?

The controversy surrounding FC has to do with authorship of the

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#### **Speaking with Kimberly**

When I began facilitating with my daughter, Kimberly, I would sometimes ask myself if she was really typing these words, or was I somehow moving her hand. To suddenly have one's daughter type long sentences when she rarely spoke one word, is an indescribable feeling. Was this the same seven-year-old child I thought only understood at the level of a three-year-old?

Yet, I knew in my heart these were her hand movements and not mine. Because of my own doubts, however, I understood when I heard "through the grapevine" that some professionals who had already worked with Kim thought I was the one doing the typing. But I had no reason to lie, and it hurt to hear that people thought I was making this up. It might have been a little easier had they expressed their disbelief directly to me—though not in front of Kimberly.

Now, more than three years later, I have no doubt that all the amazing things Kimberly types are her own words, and at least one of the original doubters has become a staunch supporter of Kimberly's abilities.

None of our friends ever thought we were lying about Kimberly's abilities. They trust me, and they know that as a mother of five children, I don't have time to go around pretending my daughter types. They know that I facilitate with Kimberly because she has something to say. Also, some of our friends now facili-

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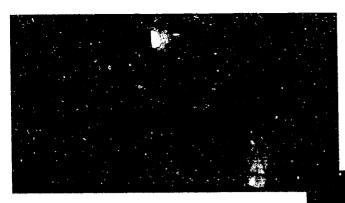
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Circle #202



419



Marityn Dixon began facilitating with her daughter, Kimberty, now 10, three years ago.

tate with her as well, so they know from personal experience that these are her words.

However, we still encounter proféssionals who doubt FC. About a year after she began using FC, Kimberly and I went to a conference where a speaker—an "expert" in the field of autism—spoke negatively about FC, even though he'd had no personal experience using the technique.

Since this speaker has never tried FC, his suspicions are understandable. However, it was not right for him to publicly criticize something he knows so little about, especially in front of an audience including many people whose children use FC.

Another time, we took our daughter to a neurologist because of her seizures. After being given a drug so she would fall asleep for an EEG, Kimberly, by facilitating with me, tried to tell the doctor how the drug made her feel. The neurologist immediately said, "Mom, what are you doing? She isn't even looking at that thing [her Canon communicator]." Although this person had never met Kimberly before that day, he was

questioning her ability to communicate. It made me feel like he thought I was ignorant and that my daughter was not intelligent. The worse part was that he said this in front of Kimberly.

Professionals would do better to assume that all non-verbal or low-verbal individuals they encounter actually understand everything that is said. Even if these individuals are genuinely retarded, it certainly can't hurt to treat them as if they are not. And if they are intelligent and the "professional" treats them otherwise, it can damage their self-esteem. I believe many professionals reject FC because it would force them to admit they had been wrong about everything

they have been taught or believed about the intelligence of those who cannot speak.

---Marilyn Dixon Texas



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#### EXCEPTIONAL PARENT / MAY 1995

#### C() MMUNICATION

spelled-out sentences. Critics believe the facilitator determines the letters to which the nonverbal individual points. In fact, many studies have shown that the pointing was controlled by the facilitator. In virtually all, the facilitators were unaware of their influence, and were shocked and dismayed by the results.

One of the most powerful of these studies was conducted in 1992 at the O.D. Heck Developmental Center in Schenectady, New York. Douglas Wheeler and his colleagues intended for their study to prove to skeptics that FC was a valid form of communication for the individuals with autism in this program. The three-month study included hundreds of trials involving 12 individuals with autism and nine facilitators. The results were completely unexpected. Not only was there not one, single correct response, the incorrect responses showed overwhelming evidence of facilitator influence.

Defenders of FC argue that studies such as this one have been done in artificial circumstances, and, therefore, are not valid. However, no studies published in peer-reviewed journals have offered support for FC.

## How could a facilitator make someone point to certain letters without being aware of it?

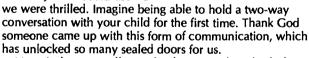
It is very possible to gently guide someone's hand to point to certain letters without being aware you are controlling their movements. This is like an imperceptible nudge made to a car's

continued on page 49

#### **Facilitating Love**

There have been times in the past that family and friends have denied that my seven-year-old son, Joshua, was really "talking" to us. They have accused us of putting ideas in his mind, of spelling what we want to hear and just making up the things that Joshua has told us. Regardless of what they say, or what the "experts" have said, I know that FC works for my son.

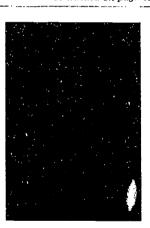
I remember the first day we learned Joshua could use FC—



Now, Joshua can tell me what he wants, how he feels and what he wants to do. But most of all, he says that he loves me. And this is something I will not let anyone take from me.

If you have not tried FC, or are skeptical about it, why not listen to your heart and give it a try with your child? Unless you find a speech therapist who is willing to try anything to help your child, you will find the going rough. But I encourage you to stick with it. If your child is able to use FC, you will certainly be rewarded.

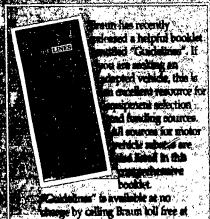
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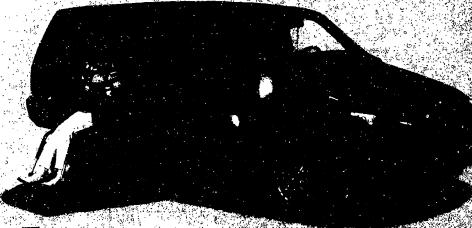












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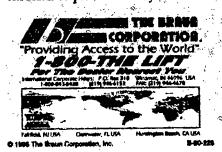
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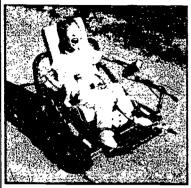
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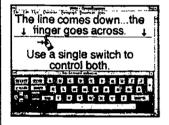
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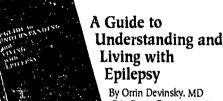
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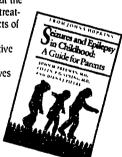
## Seizures & Epilepsy in Childhood: A Guide for Parents

By John M. Freeman, MD, Eileen P.G. Vining, MD, and Diana, J. Pillas The Johns Hopkins University Press, 1990

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#### C() MMUNICATION

continued from page 44 steering wheel as the driver thinks about making a turn.

It is natural for a facilitator to anticipate the next letter of a word—looking toward a likely letter and, without realizing it, subtly guiding the person's hand to that letter.

Does it really matter who controlls the pointing? If everyone believes the communication is coming from the child, and the child is doing so well, why does it matter? Parents and teachers report that some children show improved behavior after FC is introduced. This may be due to the fact that when FC is used, other good things happen at

the same time—the child gets a lot of positive, individual attention and close physical contact; he is often given more opportunity to express preferences, included in a greater variety of activities and treated with more respect. All of these good things can cause the child's behavior to improve, even if he or she isn't actually using FC to communicate.

If using FC only caused positive changes in the lives of children and their families, perhaps it would not matter who was controlling the pointing. But FC also poses serious risks:

- Non-preferred life changes. A facilitator may report that the child types requests that may not reflect the child's true desires. While misrepresentation of preferences regarding clothing or hairstyle may be harmless, FC messages have also led to changes in children's medical treatment and educational placement.
- False allegations of abuse. Even more serious is the fact that FC has resulted in a large number of sexual abuse allegations. When these communications are not coming from the child, and the allegations are false, the consequences can be tragic. In some cases, children have been removed from their homes. When these cases were investigated, it turned out that there was no abuse, and that the FC messages came from the facilitator.
- Elimination of effective communication methods. When a child begins using FC, his or her other forms of communication—gestures, signs or augmentative communication systems—are sometimes ignored. But if FC is not really the child's communications, these other forms of communication are vital for the child to be understood and to express his or her own, unique personality.

#### What is needed for someone to be able to communicate?

Communication is a very complex process involving a variety of intellectual, social, emotional and physical abilities. This process can pose challenges for many people with disabilities. For example, consider some steps a child might go through to obtain ice cream. Step 1: The child must be able to think about eating ice cream: he must be able to imagine eating ice cream, even though he cannot see the ice cream. Imagining something one cannot see requires a certain level of intellectual sophistication. Step 2: The child must understand that telling someone he wants ice cream will help him get ice cream! Understanding the necessity of directing communication to another person requires social understanding.

Step 3: The child must have a way to indicate what he wants—spoken words, sign language, written language, pictures, gestures or a specific behavior that those around him understand to mean "I want ice cream."

Communication can break down at any step. It is very important to find out where the problem occurs so we can add support to that part of the process.

For example, communication is affected when a child's thinking process is limited to what he or she can see (Step 1). In such cases, children can indicate preferences by being offered frequent, specific choices, such as a choice between ice cream and cookies.

For children with autism, a disorder affecting social interaction, communication often breaks down at Step 2. For example, a child may be aware that he wants ice cream (Step 1); he may even be able to say the words "I want ice cream" (Step 3); but he may not yet understand that he must direct that phrase to another person (Step 2).

Many children with autism develop unique ways of communicating that are easily understood by those who know them well. For example, one child with autism may recite a line from a television commercial for ice cream. Another may take someone's hand, lead that person to the refrigerator and look up at the freezer door. If a child's family, teachers and friends understand his or her individual ways of communicating, the child can communicate needs and desires. However, it is also important to try to teach more standard modes of communication.

Children with significant motor problems

continued on page 51

#### Position Statements on Facilitated Communication

A number of national professional groups and advocacy organizations have issued position statements on the use of facilitated communication (FC). Excerpts from these statements are reprinted below: [EDITOR'S NOTE: The Autism Society of America (ASA) has deliberated this issue over the last two years but has no plans to issue a position statement of FC. ASA stresses the importance of parents and professionals being fully informed about the pros and cons of the technique.]

"... Studies have repeatedly demonstrated that FC is not a scientifically valid technique for individuals with autism or mental retardation. In particular, information obtained via FC should not be used to confirm or deny allegations of abuse or to make diagnostic or treatment decisions."

—AMERICAN ACIDIENT OF CHILD & ACCUSENTIA, October 1993
(This position statement has also been endorsed by the AMERICAN ACCIDING PRIVATICS.)

- "... A substantial number of objective clinical evaluations and well-controlled studies indicate that FC has not been shown to result in valid messages from the person being facilitated.
- "...The Board of Directors of the American Association on Mental Retardation (AAMR) does not support the use of this technique as the basis for making any important decisions relevant to the individual being facilitated without cleer, objective evidence as to the authorship of such messages. The AAWR strongly encourages the use and further development of velid augmentative and alternative communication techniques and approaches."

AMERICAN ASSOCIATION ON MERTAL REDITIONIDIA, JUNE 1994

"...[S]pscific activities contribute immediate threats to the individual civil and human rights of the person with autism or severe mental retardation. These include use of FC as a basis for:

a) actions related to nonverbal accusations of abuse and mistrest-

ment...;

b) actions related to nonverbal communications of personal preference, self-reports about health, test and classroom performance and family relations;

c) client response in psychological assessment...; and

d) client-therapiet communication in continued on page 51



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#### C() MMUNICATION

continued from page 49

may not be able to physically form words, causing a breakdown at Step 3. For example, such a child may know he wants ice cream (Step 1), and know he needs to tell someone (Step 2), but he may not be able to make his mouth form the word in an understandable way

(Step 3). Providing this child with augmentative methods of communicating—signs, gestures, a picture board or an alphabet board connected to a speech synthesizer—will allow him to communicate successfully.

An alphabet board or keyboard, as used in

#### From Someone Who's Been There and Back

was the facilitator for a child with autism who, through facilitated communication (FC), made allegations of abuse against members of her family. I continue to struggle to understand how the use of this seemingly harmless technique could have caused so much pain to so many people.

I was introduced to FC by staff members in my school system. I had worked for five months with this particular child using traditional techniques, but I'd had little success obtaining reliable, verbal communication. Other staff members introduced the child to FC. After a few months, they reported an emergence of words.

By fall, the child was producing occasional sentences. At that time, I became her primary speech/language therapist and began to work more closely with her. Under the supervision of the other facilitators, I learned the technique.

The child resisted at first, but gradually began extending her hand to me when I sat beside her with the board. In structured, language-based activities, she began to respond in words, then phrases and, finally, sentences.

As her ability to use FC increased, the other two facilitators began to report "communications" from this child indicating anger and a desire to kill herself. Her "team" (composed of parents, teachers, administrators and special education staff) agreed that these feelings could be considered "normal" for someone who was able to communicate for the first time. No one questioned the validity of the communications.

By mid-winter, the other facilitators and I were using FC to have "spontaneous" conversations with this child. These conversations seemed to be student-initiated. Her "communications" often centered on feelings of anger and frustration. Eventually, she alleged that she was being hit by family members.

We agreed not to report our "findings" until we were sure of what we had. We continued documenting the conversations and watching for behavioral or physical changes. I feared for the child's safety and speculated on the conditions of her life at home.

Shortly thereafter, during a "spontaneous" conversation this child "stated" she was being abused by her father. The description was specific enough to warrant concern. We reported the findings to the Department of Human Services (DHS). During the three-hour interview with DHS, this child, through FC, graphically described events of sexual abuse. DHS authorities removed her and a sibling from their home.

DHS appointed a guardian ad litem (a lawyer hired by the state to protect the rights of the

child) who arranged testing to find out if the communications were coming from this child.

In the meantime, I attended an FC workshop at a local university. As the workshop leader reviewed a "checklist" for facilitating correctly, I realized the child I was working with did not always look at the board. Although the workshop leader pronounced my technique "exactly right," I was concerned. I asked the leader and other "experts" if they had ever worked with students who did not look at the board. They all said they had, and that they believed their clients had memorized the board's layout.

I came away from that workshop even more convinced that FC worked. The workshop leaders acknowledged negative validation studies, but said those studies were flawed.

On the day of the child's FC test, I felt nervous, but confident the results would support the validity of her communication. This test included picture identification, story comprehension, handson activities and short-answer questions that she should have easily known. The child seemed to enjoy the activities, and I felt she was communicating in her usual way.

The results devastated me. Not one of her answers was correct. In fact, the picture-identification section clearly showed that "her" answers described the objects I had seen. The abuse charges were dropped.

A few weeks after the testing, I read those negative studies. I could no longer ignore the fact that the communications were coming from facilitators and not the clients. I convinced my employer to stop using FC.

Still, I carried guilt and shame for my role in bringing charges against this child's family. I knew I could not heal from the experience unless I apologized. A year later, I sat down and talked with the family. Although they were extremely hurt by the experience, her father told me they understood how I became involved. They had also wanted to believe in FC.

---Janyce L. Boynton Maine

This piece was adapted from The IARET Newsletter (Summer/Fall 1994), published by the International Association for the Right to Effective Treatment (IARET). IARET (763 Main St., #10, Waltham, MA 02154-0604, 617/891-7554/voice and fax) is an educational and advocacy group helping to ensure that all individuals with disabilities "benefit from the most progressive, effective interventions possible." Annual newsletter subscription is \$9 for three issues.

Position Statements on Facilitated Communication continued from page 49 counseling or psychotherapy...

"...[F]acilitated communication is a controversial and unproved communicative procedure with no scientifically demonstrated support for its afficacy."

— AMERICAN PSYCHATRIC ASSOCIATION, AUGUST 1994

"...When information available to facilitators is controlled and objective evaluation methods are used, peer reviewed studies and clinical assessments find no conclusive evidence that facilitated messages can be reliably attributed to people with disabilities... Moreover, FC may have negative consequences if it precludes the use of effective and appropriate treatment, suppliants other forms of communication, and/or leads to false or unsubstantiated allegations of abuse or mistreatment.

"...Information obtained through or based on facilitated communication should not form the sole basis for making any diagnostic or treatment decisions.

"ASHA strongly supports continued research and clinical efforts to develop scientifically valid methods for developing or enhancing the independent communication and literacy skills of people with disabilities..."

— American Speech-Language-Hearing Association (ASHA), October 1994

"TASH regards access to alternative means of expression [as] an individual right.

"TASH ancourages its membership to become informed about the complexities of FC training and practice and to stay informed of new research... TASH encourages people who decide to become facilitators to seek training... TASH encourages careful, reflective use of FC. TASH encourages facilitators to work in rollaboration with individuals with severe disabilities to find ways of confirming communication competence when using facilitation...

"TASH urges that when allegations of abuse or other sensitive communication occur, facilitators and others seek clarification of the communication and work to ensure that users of facilitation are given the same access to legal and other systems that are available to persons without disabilities. It is important not to silence those who could prove their communication competence while using facilitation or any other method of expression..."

---TASH (The Association for Persons with Severe Handicaps), October 1992



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FC, can only address communication problems that occur at Step 3. It cannot fix problems at Step 1—the "thinking" part of the process, nor can it fix problems understanding the social use of communication (Step 2).

And FC can only help with problems at Step 3 if the child is able to spell words and sentences, but is not able to point or indicate letter choices independently. However, any child with the ability to spell and write sentences, and the motor ability to guide an adult's hand to specific letters, has the potential to develop *independent* communication skills through augmentative communication. A child who does not have the thinking skills to write and spell, or the necessary social understanding for complex communication, would not be able to use FC, but may benefit from some form of augmentative communication.

#### At school they are using FC with my child. What should I do?

If your child's teachers, speech therapists or other professionals are using or suggesting the use of FC, we suggest the following steps:

- Consider whether the sentences produced, and the spelling and grammar abilities, are consistent with your child's abilities as you and professionals know them.
- If you believe your child is communicating successfully with FC, he or she is an excellent candidate to be able to

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quickly learn to use an advanced augmentative communication system. Recommend that the child be evaluated for this type of communication aid.

- If FC is being used and you believe the communication is being controlled by the facilitator, it is important to meet with your child's team and discuss your concerns. The communication methods used at school must be consistent with your child's IEP. If FC is not in your child's IEP, you should not have difficulty eliminating its use. The team should work with you to explore other communication methods.
- Most importantly, to einsure that your child is working with the most optimal communication methods, a thorough evaluation of your child's cognitive, social, motor and communication abilities can help the team understand and address any problems interfering with his or her ability to communicate. Such an evaluation can be done through the school, however, if there is disagreement about an optimal communication approach, you have the right to an independent evaluation paid for by the school once they have done their own evaluation. An independent evaluation can provide objective input regarding optimal communication approaches. EP

Karen Levine, Ph.D., is director of psychology at the University-Affiliated Program, Institute for Community Inclusion, Children's Hospital, Boston, Massachusetts. She is also an instructor at Harvard Medical School. Karen specializes in psychological consultation for children with autism, Williams syndrome and other developmental disabilities, and their families.

Robert Wharton, M.D., is chief of developmental pediatrics and rehabilitation at Spaulding Rehabilitation Hospital and chief of pediatric rehabilitation at Harvard Medical School. Dr. Wharton specializes in medical care and behavioral consultation for infants and children with complex medical problems, injuries and/or developmental disabilities.

#### To learn more about FC...

- Facilitated Communication: The Clinical and Social Phenomenon, published in 1994 and edited by Howard C. Shane, Ph.D. of Children's Hospital in Boston, provides an up-to-date look at the what is currently known about FC. Topics include history, legal issues, research methodology and research results. Available from Exceptional Parent Library (800/535-1910); \$45.
- The American Speech-Language-Hearing Association (ASHA) has issued a technical report on FC. The report was developed by a committee, which included both professionals and parents. The 47-page report, released in October 1994, provides a detailed overview of FC, with an appendix summarizing the methodology and results of every published research study on the subject. Also included is a four-page minority statement issued by two committee members who disagree with some conclusions of the technical report. These materials may be obtained by sending a selfaddressed 12 x 9-inch envelope stamped with \$1.93 in postage to ASHA, Information Resource Center, 10801 Rockville Pike, Rockville, MD 20852; (800) 638-8255 (V/TTY), (301) 897-7348 (fax).

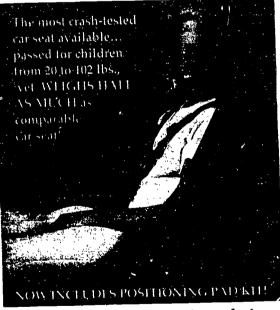
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431

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## **Using the Telephone**

by Susan Phillips

e have all heard stories of the three-year-old who dialed 9-1-1 and saved his parent's or sibling's life.

Learning to use the telephone is not only fun for children, but an important daily living skill as well.

These days, the telephone is used for everything from shopping to banking. However, a child with a hearing impairment or an inability to speak clearly may not be able to use the standard telephone.

#### **Modifications**

Fortunately, many relatively simple modifications can enable children with hearing impairments to use the telephone. For instance, a child with a mild or moderate hearing loss may be able to use a standard telephone with an amplified handset and volume control. When purchasing these handsets, bring the telephone to the dealer to match the color and brand. Slip-on

amplifiers, which fit over the earpiece of the receiver, can be purchased from Radio Shack for as little as \$20.

Another option is to buy a behind-the-ear hearing aid that includes a telecoil with Tasha is all smiles as

Tasha is all smiles as she talks to her mom on the telephone using a special amplifier attached to the earpiece.

a switch that lets the aid receive sound directly from the telephone rather than from the aid's external microphone. This option has the added benefit of tuning out environmental sounds or background noise.

For children with more severe or profound hearing losses. or those who cannot communicate well through speech, a teletypewriter—commonly called a TTY—may be the answer.

continued on page 56

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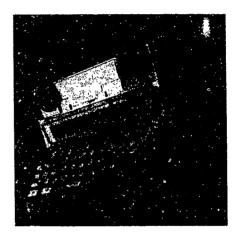
continued from page 55

Other names for TTY are "TDD," which stands for "telecommunications devices for the deaf," or, less common, "TT," which stands for "text telephone."

TTYs include a typewriter-like keyboard and view screen. The handset of a standard telephone fits into rubber cups on a cradle, which is built into the TTY. (In older TTY models, this modem-like device is an attached appliance called a "coupler.") A monitor light on the TTY (or, in older models, its coupler) indicates the status of the outgoing call—a steady light indicates a dial tone; the

light flashes to indicate rings or a busy signal. The TTY user types outgoing messages on the keyboard and reads incoming messages as they appear on the view screen. Since a TTY is used with a standard phone, any special features on your own telephone, such as rapid dial, are also available for the TTY.

TTY prices range from \$280-\$500, depending on optional features such as built-in answering machines, printers and additional memory to store messages. Some TTYs plug right into a phone outlet and have a dial function,



Portable fold-up TTYs are becoming increasingly available. Photo courtesy of Ultratec, Madison, WI.

eliminating the need for a telephone. TTY modems, which allow one to use a computer as a TTY, are also available. These modems typically cost about \$300.

'TTY relay services—available in every state and through major long-distance carriers—act as intermediaries between TTY users and users of standard telephones. A deaf child who uses a TTY could use a relay service to call her grandmother, who may not own a TTY.

"Voice carryover" (VCO) is an option built into some TTY models, or available through most relay systems. With VCO, a person can speak into the receiver while receiving typewritten messages from the other person, or listen to incoming messages while typing outgoing messages. This allows someone who

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Making a call using a Memory Printer TTY, Model MP2000, made by International KROWN Technologies, Inglewood, CA.

can speak but not hear, or someone who can hear but not speak, to make more efficient use of time on the telephone. To set up your home phone system to use VCO through a relay service, you need only a "double modular jack" (about \$5, available at Radio Shack), which allows the TTY and the telephone to be hooked into the same phone line.

To alert someone with a hearing impairment to a telephone call, devices such as flashing light systems are available. In addition, personal vibrating devices work like beepers and can include lights of different colors to indicate whether an incoming signal is coming from the telephone, the doorbell or the smoke alarm.

Special telephone access systems are available for children with hearing impairments, motor difficulties or both. These include voice-activated phones or remote-control speaker phones that can be activated by a switch mechanism.

#### Special services

Currently, about 33 states have adaptive telecommunications equipment distribution programs, which distribute free or reduced-cost telephone equipment to children and adults with disabilities. In addition, many major long distance phone companies—including AT&T, MCI and Sprint—provide relay services and may also offer additional benefits, such as discounts on long distance calls for homes with TTY machines. For more

information on state programs, long distance services and other information about TTYs (including local resources), contact Telecommunications for the Deaf, Inc. (TDI), 8719 Colesville Rd., Ste. 300, Silver Spring, MD 20910, (301) 589-3786, (301) 589-3006 (TTY), (301) 589-3797 (fax).

Susan Phillips, M.Ed., CCC-A, is an audiologist at the Kennedy Krieger Institute in Baltimore, Maryland. She has a master's degree in deaf education and is a doctoral candidate at the University of Maryland. Her grandparents are deaf.

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#### HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

#### Long-term Physical Therapy; Wheelchair Ramps

Our health insurance will not pay for long-term physical therapy for our child unless he shows "measurable progress." The therapist says that without long-term physical therapy, my child will develop secondary medical problems, such as contractures, which will be costly in the future.

A Insurance policies generally cover treatments that are related to existing medical conditions or illnesses. They don't usually cover preventive care.

Although insurance companies may cover the treatment of a contracture (when a joint loses normal movement and becomes static), they will not usually cover physical therapy designed to prevent contractures, or to maintain a particular range of joint motion.

#### Development of health insurance

When health insurance was developed in the United States, preventive care, doctor visits and medical tests were relatively inexpensive. Thus, health insurance was originally designed to cover the more expensive hospitalization and surgery.

As doctor visits and medical tests became more expensive, they were added to the list of covered items. The guiding principle, however, seems to have been to provide coverage for treatment for medical conditions or illnesses, not for prevention. However, in the past few years, some new insurance programs have begun to cover some types of preventive care.

These days, the fact that a patient is making progress in physical therapy may be viewed as evidence that the therapy involves treatment, rather than prevention or maintenance. In your son's case, progress may be defined as a positive change in the range of motion of a particular joint, or an improvement in the child's ability to move more easily in specific situations.

If this type of progress is occurring and continues, and the insurance company does not pay the claim, file an appeal. Write "Claim Appeal" on the envelope and on the letter asking the company to re-evaluate its decision. Include letters from your child's doctor and therapist describing the therapy's purpose and documenting any progress that has been made.

If no progress appears to be occurring, I don't think your insurance company is likely to cover the therapy. However, if your child is in school, and the contractures interfere with educational activities, the school may agree to pay for physical therapy that takes place at the school. It's important to include the therapy on your child's Individualized Education

In my March column ("A New Insurance Plan for Individuals Considered 'High Risk'"), I discussed a new health Insurance program, offered by the Arc, designed to meet the insurance needs of children and adults with disabilities.

Although the Arc originally planned to offer the insurance program nationwide, it apparently cannot yet be offered to residents of New Jersey, Connecticut, Vermont or New Hampshire because of certain state insurance regulations. The Arc is working to solve this problem.

---R.E.



Plan (IEP) because school districts are legally obligated to provide all services listed on the IEP.

My insurance will pay for my child's wheelchair, but the policy will not pay to install a ramp on our home. That means we have to lift our child, and his wheelchair, to get him in and out of the house. We would like him to be able to go outside independently.

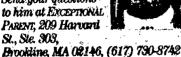
Health insurance is designed to pay for medical equipment, and not for non-medical equipment or architectural modifications. However, trying to predict what will be considered "medical equipment," and what will not, can sometimes be difficult.

An electric wheelchair, for example, is considered "medical equipment." Insurance policies will generally cover an electric wheelchair, as long as it meets the requirements to be classified as a "medical necessity." However, a wheelchair ramp (and lift, too) will not usually be covered because it is considered "non-medical."

#### Finding help

Insurance is not the only source of help in trying to build a wheelchair ramp. Many volunteer organizations may build a ramp for free. The Telephone Pioneers of America, a group of volunteers from AT&T, Canadian phone companies and local phone companies, may build a ramp, or do other architectural or engineer-

In this column,
Richard Epstein
answers readers'
questions about
health insurance.
Send your questions
to him at Excertions
Paper 200 Harron



If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters include them.

ing projects for you.

Local chapters offer different services. For your nearest chapter, contact Telephone Pioneers of America, 930 15th St., Denver, CO 80202.

Your local independent living center may have information about other groups that may help build or provide funding for your ramp. Local Parent Training and Information Centers

(PTIs) may have similar information. (A directory of PTIs can be found in the 1995 Exceptional Parent Resource Guide.) State agencies, such as divisions of vocational rehabilitation services, health departments and developmental disabilities agencies, may also provide some funding or advise you of other possible funding sources.

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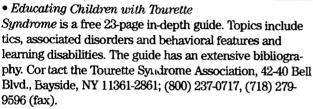
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#### WHAT'S HAPPENING

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#### **Publications**

• Guidelines: Choosing the Right Mobility Equipment is a primer for people with disabilities who are looking for their first adapted van. This free booklet discusses considerations associated with being a passenger or driver, finding a vehicle to adapt, full-size vans versus minivans, lift options and finding help in paying for a van conversion. Contact the Braun Corporation, 1014 S. Monticello, P.O. Box 310, Winamac, IN 46996; (800) 843-5438, (219) 946-4670 (fax).



 IN Motion is a new publication that offers information and guidance for people with limb disorders or amputations. Articles will address sports and recreation, physical therapy tips, new technology and product information. For a free copy, contact *IN Motion*, Amputee Coalition of America, 1932 Alcoa Hwy., Knoxville, TN 37920, (800) 355-8772.

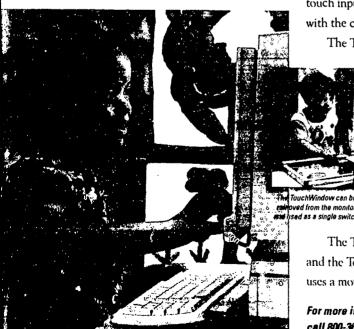
• Learning Together is a free newsletter published twice a year (June and Dec.) to connect parents of children with autism or related disorders for "friendship, encouragement and information." Readers can list themselves in the newsletter if they want to find pen pals. For a copy, send a self-addressed stamped envelope to Annette Vander Weide, 149 E. Cortner St., Hanfrod, CA 93230. For a pen pal listing, include a paragraph describing yourself.

#### **Videos**

• Parents Can Make a Difference is a 90-minute, open-captioned video for parents of children who are deaf or hard of hearing. Topics include parent support, tips for parents in rural areas and the IEP process. The video features three parents sharing their experiences. Free to Minnesota parents; \$10 for others. Send payment (payable to the Minnesota Foundation for Better Hearing and Speech) to the Parent Network, MFBHS, 166 4th St. East, Ste. 320, St. Paul, MN 55101; (612) 223-513) (V/TTY).

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For more information or a free product catalog, call 800-362-2890.



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Circle #109

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#### 1995 Special Olympics World Games

Special Olympics invites proud families, relatives and friends of its outstanding athletes to join in the fun and excitement at the 1995 Special Olympic World Games in New Haven, Connecticut, July 1–9.

Connecticut, July 1–9.
Athletic events will also take place in West Haven, Hamden, New London and Old Lyme, Connecticut.

Share the job of cheering 7,000 athletes representing 140 countries from around the world. Join thousands of other family members and friends who will gather to support these spirited athletes as they participate in the largest and most exciting sports event of 1995.

The 1995 Special Olympics World Games Family Services Committee will provide hospitality and information to the families of the athletes who will attend the games. Centrally-located family centers will provide a place for families to relax, meet others and have refreshments. A main family center will be located at the Yale Bowl; satellite centers can be found at other sports venues. The main center will feature ent rtainment, a children's play area and daily competition schedules. A siblings program for brothers and sisters of athletes, aged 8 and older, is also planned.

An extensive shuttle transportation system will be available to transport families between sports venues. It is also expected that transportation will be available from area hotels and towns.

For travel and car rental information, contact Adelman Travel, the World Games' official travel agency (800/666-8886). For information about New Haven area hotels, motels, bed and breakfast inns, call the Greater New Haven Convention and Visitor's Bureau (800/332-7829).

And be sure to stop by and visit with *Exceptional Parent!* You'll find our booth at the family center at the Yale Bowl.

**Support Groups** 

• Twin-to-Twin Transfusion syndrome (TTTS) is a condition, which sometimes occurs in pregnancies involving identical twins or higher multiples, when blood passes disproportionately between one baby and another through connecting blood vessels in a shared placenta. Survivors of TTTS

may be left with a number of serious disabilities, including cerebral palsy. The Twin-To-Twin Transfusion Syndrome Network (2592 W. 14th St., Cleveland, OH 44113; 216/731-6940; 216/585-2626, fax) provides support and information to families and medical professionals through meetings, participation in conferences and a quarterly newslette...

• Myasthenia gravis is a chronic neuromuscular disease marked by weakness and muscle fatigue. The Myasthenia Gravis Foundation of America (222 S. Riverside Plaza, Ste. 1540, Chicago, IL 60606; 800/541-5454, voice; 312/258-0461, fax) is

starting a pen pal network for parents of children with myasthenia gravis and for teenagers with the condition.

#### **Autism Research**

The National Alliance for Autism Research (NAAR) is a non-profit organization dedicated to funding and promoting biomedical research into the causes, prevention and treatment of autism and related developmental disorders. Run by parents, NAAR is the only organization in the U.S. dedicated solely to fundraising on behalf of increased medical research in autism. NAAR plans to award research grants, publish a newsletter, sponsor symposia for researchers and support the work of the brain bank at Massachusetts General Hospital, a major source of research on neurological studies. For more information, contact NAAR, Two Center Plaza, Ste. 420, Boston, MA 02109; (508) 470-4747, (908) 359-9957. NAAR's Internet address is naarlondon@delphi.com. EP



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# TAKING CHARGE Overcoming the Chain that ARINE POLITIN M.S.W. A SUSAN K. GOLANT

#### MEDIA

agazine editors get many books from publishers, eager to have a current book receive a favorable review. In an effort to keep up with these, I often take a few along for onairplane reading. I tend to be semi-conscious at such times, and many books serve as a sedative to help me

sleep. Those were the circumstances under which I began reading Taking Charge: Overcoming the Challenges of Long-Term Illness by Irene Pollin, a psychiatric social worker. Very quickly, I was wide awake and excited. This was a terrific book! Although the book was written specifically for individuals with long-term illnesses, every chapter is filled with powerful information and helpful support for parents and other family members.

In fact, Irene Pollin is a parent as well as a psychiatric social worker. After the loss of two of her own children, she returned to school for training as a psychiatric social worker. After 20 years of research and work in family counseling, she developed "medical crisis counseling," a new model for working with individuals with chronic illnesses and their family members. This model of counseling is focused on the medical crisis, not on personal or family history.

In dealing with her children's illnesses, Pollin became aware that professionals receive scant training to help individuals and families cope with long-term effects of chronic illness or disability. Neither mental health nor medical specialists provided the support she and her husband needed. In addition to writing this outstanding book, Pollin established the Linda Pollin Foundation, named after her late daughter, which—in collaboration with Children's Hospital in Boston—provides this specific training to mental health and other health-care professionals. In Pollin's words—"I have discovered that by confronting and taking charge of your fears, you can learn to accept your for your loved one's long-term condition. Indeed, you can once again take charge of your life. This book will show you the way."

Thousand of parents and professionals first learned about Exceptional Parent from nationally-syndicated columnist Ann Landers; here's what she says about Taking Charge: "[This] book... should be required reading for everyone facing the challenge of long-term illness, whether their own or that of a loved one... It could be the most valuable gift you will ever give."

Beginning with this issue, Exceptional Parent presents a series of excepts from Taking Charge.

-Stanley D. Klein, Ph.D.

TAKING CHARGE is available from Exceptional Parent Library (800/535-1910). The following is an excerpt:

#### **Identify Your Problems**

Knowledge is power. In order to handle the problems you're bound to encounter, you must first be aware of them. As painful as it may be, with awareness comes the possibility of adjustment, integration and resolution. Without it, you may become stuck, confused or embittered. With insight, however, you can anticipate the rough spots. Because you can expect certain challenges, you prepare for them and learn how to handle them, thus diminishing their effect on you.

To help visualize the complexity of problems inherent in coping with long-term illnesses, picture a pane of safety glass that has been hit very hard by a sharp object such as a small stone. The glass doesn't shatter and fall to the ground. Instead, immediately around the center of impact, a web of fine cracks appears. The network grows, radiating in every direction. Some fissures are short, others long. Some spread directly from the center while others intersect. All the fractures are connected, even those at the farthest edges of the pane, because they result from the same impact. Although the glass is more fragile than before it was hit, it still remains whole in its fractured state.

So it is with your long-term illness. You will encounter a myriad of intersecting medical, social, emotional and economic problems. There are the obvious physical disabilities to overcome: pain; restricted movement, activities or diet; dependency on medication and medical technology; to name a few. In addition, your relationship with family and friends may change. You'll confront the often intimidating medical profession. Your income and savings may diminish, possibly altering your social status. Your loved ones—the major source of emotional support—may feel as vulnerable and helpless as you.

Anyone who denies being overwhelmed at this time is simply not telling the truth. Yet, even as you consider the number of problems resulting from the impact of long-term illness on your life, you'll recognize that although weakened and perhaps impaired, you remain the same person. Like the pane of glass, you've been hard-hit but you are whole and you are capable of adjusting to the fate you have been dealt.

Consider making a flow chart or diagram showing (and concretizing) the intersection of the problems arising from your illness as the fissures in a cracked pane of glass. Put your illness in the middle and draw and label the issues you must deal with as lines radiating from the center or intersecting with one another. Then draw a circle around your design to show that wholeness still exists, despite the disease. This exercise can help you bring your own problems into focus, so you'll know what you're up against. **EP** 

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4 40

#### ASK THE DOCTOR

by David Hirsch, M.D.

#### "Smart Drugs;" Undiagnosed

We have heard a lot about "smart drugs," especially for children with Down syndrome. Recently on the news show Day One, a drug called Piracetam was shown to help learning ability in a child with Down syndrome. Our son is six years old and has Down syndrome. We would be interested in anything that may help him reach his full potential. What do you think about the use of these new drugs?

The use of the so-called "smart A drugs"—as well as vitamin, mineral and amino acid supplements-is a very controversial area in the treatment of children with certain developmental disorders. Recently, there has been much publicity regarding "smart drugs," specifically Piracetam, as a supplement for children with Down syndrome. Piracetam, often used in conjunction with other supplements (typically vitamins, minerals, amino acids and, sometimes, digestive aids or enzymes), is one member of a new class of drugs that are thought to enhance learning and memory. No commonly accepted mechanism of action has been established: that is, if it works, we are not exactly sure how or why.

Piracetam (trade name Nootropil) is considered an orphan drug. An orphan drug is a drug still in clinical testing and not yet approved by the Food and Drug Administration (FDA), or a drug designated for use in rare disorders affecting 200,000 people or less. Piracetam's only indicated use is for a rare condition called myoclonus (a type of seizure disorder); its use is not indicated for learning disabilities, mental retardation or Down syndrome. In fact, at this time, I do not believe Piracetam

can be legally imported into the U.S. Also, because of a lack of appropriate scientific research on the use of the drug in individuals with Down syndrome, the National Down Syndrome Society does not recommend the use of Piracetam for children with Down syndrome.

I wholeheartedly agree that any child—regardless of disability— should be allowed to reach his or her full potential. Certain less conventional therapies—such as drugs or other nutritional or vitamin supplements—may have a role if used in a cautious manner. And any such supplements should be used only in conjunction with more conventional medications, helpful therapies, an appropriate educational program, a nutritious diet and appropriate exercise.

If you wish to consider the use of any of these "smart drugs" or other supplements, I encourage you to check with your son's pediatrician to make sure no other medical, therapeutic or educational options need to be considered first. Your son's pediatrician can also assess the possibility of any drug interactions. Under no circumstances should one assume that if a certain amount of a vitamin or supplement has been shown to be helpful, then twice as much (or more) of that substance will be even better.

Our eight-year-old daughter has global developmental delays (fine and gross motor and cognitive delays). Over the years, we have taken her to many neurologists, specialists in developmental disabilities, occupational and physical therapists, psychologists and pediatricians. None of these specialist has been able to give us a definitive diagnosis

for our daughter's problems. My wife and I are uncomfortable with this situation. We are also worried about any future children we may have. Can you think of anything else we might do?

You have done a significant amount for your daughter already. Lack of a specific diagnosis is one of the most frustrating situations for patients, parents and physicians. Patients without a specific diagnosis often tend to be "placed" into broad descriptive-based categories that describe symptoms such as hypotonia (low muscle tone), developmental delay, non-specific learning disability, encephalopathy (a disease of the brain, either unchang-

continued on page 68

In this column,
David Hirsch, M.D.,
a pediatrician and
member of the
EXCEPTIONAL
PARENT'S Editorial
Advisory Board,
answers questions
from readers. Dr.
Hirsch is a partner
in Phoenix Pediatrics, Ltd. in
Phoenix, Arizona. He specializes in
treating children with developmental
disabilities and chronic illnesses.

Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with appropriate professionals. Dr. Hirsch mentions specific products or medications only to illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 08146-5005, (617) 730-8742 (Pax).



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#### ASK THE DOCTOR

continued from page 67

ing or progressive) or cerebral palsy (when used in its broadest sense to mean muscular impairment or poor coordination).

Such general classifications can make it difficult to design and obtain insurance coverage for appropriate therapies and treatments. It can also make it more difficult to qualify for certain state and federal health programs that allow coverage only for certain specific "diagnoses." And parents of a child without a diagnosis are less likely to find appropriate support groups or other resources.

Family and friends may be surprised that you have not found an "answer" to your daughter's problems. You are probably getting a number of unsolicited "answers" and opinions from well-meaning family members and friends.

If you have not already done so, you should consider a genetics consultation. This would include a detailed look at your family history, chromosome studies and an evaluation of your daughter's symptoms and appearance to see if they fit any particular syndrome. This type of consultation might also address your anxieties with regard to any future children.

Medical knowledge changes rapidly, so more information about your daughter's condition may become available in the next few years. In the meantime, even without a diagnosis, you need to continue to deal with your daughter's needs for occupational, speech and physical therapy, and to make sure she is in a school program that best meets her educational needs.

Over the years, I have seen many patients who were undiagnosed; some remain undiagnosed. But their parents, like you, have accepted these children just as they are. Parents have taught me that whether a child has a specific diagnosis or not, that is the most important thing you can do. **EP** 



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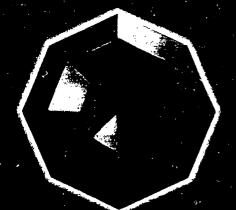
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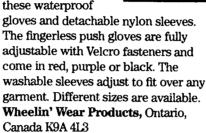
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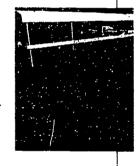
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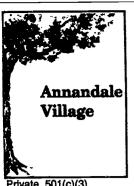
surface needs little maintenance and can be installed and used in almost any weather. These non-toxic, recycled plastic tiles have drainage holes. **Bike Track, Inc.,** Woodstock, VT 05091

Circle # 198

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on Exceptional Parent's "Free Product & Information Card." Readers can circle a number on this issue's card (page 63) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this paye), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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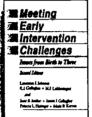


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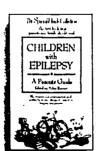


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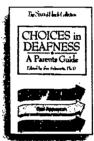


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#### CHILDREN'S PAGE

#### SIGNING WITH My Sister

by Preston Timperlake

y sister, Genelle, is deaf. I communicate with her by using sign language and by talking. When her hearing aids are off, or if there is any noise, talk-

ing doesn't work, so I use sign language. Using sign language is lots

of fun because you don't have to talk.

Genelle has deaf and hearing friends, and so do I. Daniel, my best friend, who lives in Virginia, has a sister, Kristie, who is also deaf. Sometimes, Genelle calls Kristie on the TTY. We all got together last year at the American Society for Deaf Children convention in Florida.

I have been teaching some signs to my kindergarten class. My friends enjoy communicating with the signs they have learned. When I sign with my hearing iriends, they try to guess what I am saying. When they ask how I learned to sign, I say, "I learned it from my sister, Genelle. My sister is the only deaf person in my family. I can sign to her anytime I want."

Last year, Genelle and I played on the same T-ball team. Sometimes I signed to tell her what other people were saying. During the games we signed across the field because Genelle couldn't hear the coach. That made me feel happy because I was signing to Genelle, and she is one of my best friends.

My mom is president of the American Society for Deaf Children. She tells a lot of people how important it is to be able to communicate and to understand what people are talking about. All the people in our family can sign, even my little sister. Erin. She can sign "milk" and "Dad" and a few other

words. Our baby-sitter is also deaf. We comlanguage. municate with her by signing, not talking. We sign together when she reads me stories. She tells me I think like a deaf person, and I like that! **EP** 

the family has learned sign



Hold on! Genelle was interrupted while using

the TTY during a phone conversation with a

Preston, 6, attends kindergarten at Wilson Elementary School in Corpus Christi, Texas. He lives in Corpus Christi with his sisters, Genelle, 8, and Erin, 4, and his parents, Roger and Benna. He loves to play soccer, baseball and computer games.

Siblings Preston, Genelle

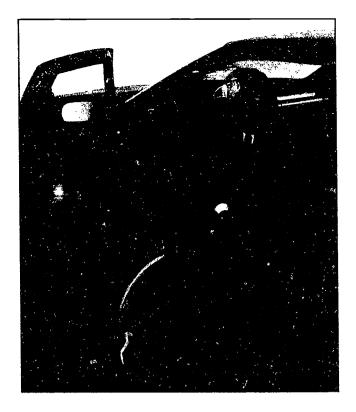
and Erin wave to the camera

two years ago. Everyone in

Genelle, who was born profoundly deaf, is a third-grader at St. James Episcopal School, with support from a sign interpreter and a teacher certified in deaf education

'he Children's Page welcomes contributions from children with disabilities and their siblings. Be creativel Send your stories, photos and artwork to: Children's Page, Exceptional Parent, 209 Harvard Street, Sulte 303, Brookline, MA 02146-5005.

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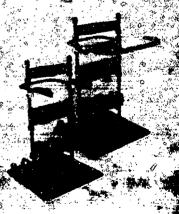
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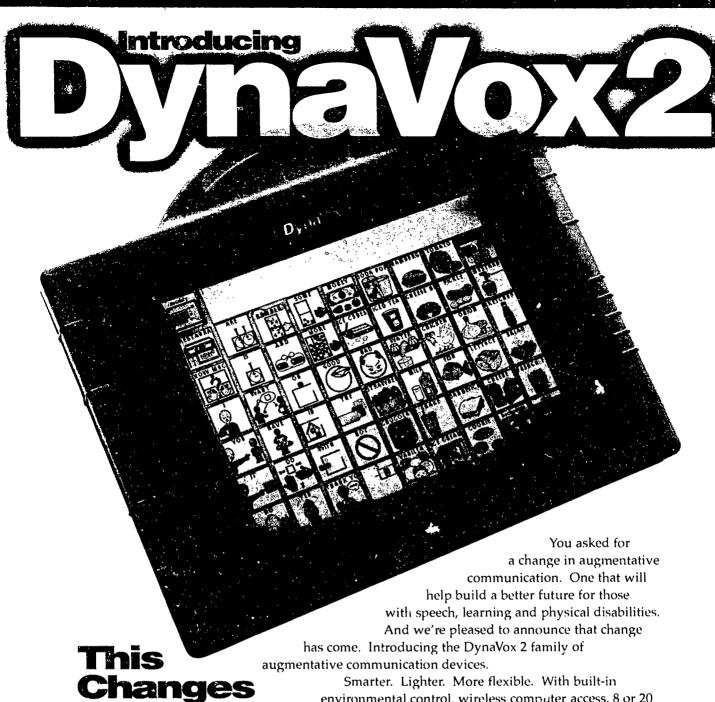
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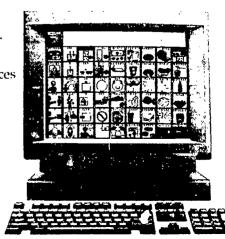
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PARENTING The Magazine for Families and Professionals

JUNE 1995 VOL. 25, ISSUE 6



PAGE 6

# Your CHILD OR YOUNG ADULT WITH A DISABILITY

Since 1971

Cover: Unified Sports competition. in which athletes with and without mental retardation play on the sane leams. was first introduced at the 1991 International Special Olympics Summer Games with three sports and 100 athletes. Just four years later, the 1995 Special Olympics World Games. held July 1–9 in New Haven. Connecticut. will feature Unified competition involving more than 1,000 athletes and 11 sports. Read more about Unified Sports in this issue. beginning on page 56. Photo: Special Olympics Unified Sports.

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#### RECREATION

Unified Sports Gains Momentum at '95 World Games by Michael Janes	56
People with and without disabilities on the same sports teams.	
Special Olympics State Chapters	60
Focus on Fitness by Naomi Angoff Chedd	
Recreation Resources	76
Using Ordinary Toys for Kids With Special Needs: Outdoor Fun by Joanne and Stephanie Oppenheim	00
Features	
<b>Talking With Your Child About Disabilities</b> by Chad Pierro	92
Readers Talk About: Helping a Child Learn About His or Her Disability	93
FOLLOWING MY HEART by Debbie Madsen	93
SHE NEEDED TO SEE WINNERS by Diane Mitchell	96
LEARNING THE "ABILITY WORDS" by Jan Moss	96
Practice! by Cara McCulley	98
STAR OF THE TEAM by Pam Spilbeler	99
What's in a Name? by Kathleen Adams	100
Getting Off to a Good Start by Jeannie Lancaster	
Departments Editor's Desk	9
Letters.  Search & Respond  Familiar Faces  Fathers' Voices: Loving Sarah by David L. Parsons  Role Models: Marry Verdi-Fletcher.  Children's Health Notes.  Health Insurance Troubleshooter: The Katie Beckett Waiver.  Media: Taking Charge  Informational Forum: Networking	28 43 48 68 104 108 110
Ask the Doctor: Fragile X Syndrome	Ц/
Exceptional Parent Library	<u>118</u>
What's Happening.  Research: The Special Parents Project by Bruce Robinson and Lorna Calford	122
You can contribute to a "survival guide" for new parents.	
Directory of Advertisers	122
New Products	125
Children's Page: Play Bala! by Serena Cucco	132

#### EDITOR'S DESK

#### **Congratulations, Special Olympics!**

In 1968, the first International Special Olympics Games were held in Chicago, One thousand athletes with mental retardation-from 26 states and Canada-competed in track and field, floor hockey and aquatics. This summer, from July 1-9, at the ninth

STANLEY D. KLEIN, PH.D.

Special Olympics World Summer Games in New Haven. Connecticut, more than 7,000 athletes from some 140-plus countries will compete in 21 sports!

The Special Olympics success story is like so many others—a story of the ways parents, family members, people with disabilities and advocates have changed the world for people with disabilities, their families and their communities. When Eunice Kennedy Shriver started a summer day camp for children and adults with mental retardation and encouraged their participation in a variety of sports and physical activities, many people considered her efforts "unrealistic." When you watch the Games this summer, in person or on

television, or read about the Games in the media, think about that word---"unrealistic"—and how often we still hear it used in reference to individuals with disabilities. Thankfully, leaders like Mrs. Shriver and others, whose names are not so well-known, have pursued their visions and made dreams become "real."

Special Olympics has also been open to change. As "inclusion" entered our vocabulary, Special Olympics initiated "Unified Sports." See our report in this issue.

As this issue illustrates, recreation includes a number of activities. In the past, many children and young adults with disabilities were discouraged from pursuing recreational activities. Some well-meaning people feared that an individual's self esteem might be irreparably damaged by his or her inability to "keep up" with peers in competitive activities. Fortunately, we are now learning that all people can enjoy active participation, even when their own talents in an activity may be limited. For generations, many people have enjoyed watching star athletes perform without feeling badly about their own more-average athletic abilities. Nonetheless, it seems many have needed to see the success of programs like Special Olympics to appreciate the value of participation.

#### Talking about disabilities

Most parents will agree that it is helpful to talk about children's disabilities with them. But it is not an easy task and there are few guidelines. As usual, however, when we asked, our readers came through to share their ideas on this topic. You can read some of their stories in this issue.

#### Planning ahead

In 1996, we will mark Exceptional Parent's 25th anniversary. As we began planning for this milestone, we welcome suggestions from readers—ideas for "special features" to include in an anniversary issue, as well as ideas for our 1996 editorial calendar. Be creative-no suggestions will be considered unrealistic!

#### Special advertising supplements

This is the second issue in 1995 that includes a special advertising supplement. When we collaborate with companies on these types of projects, it is because we are confident that their programs or products are, in fact, special. In April, the Rifton Company sponsored a report about the MOVE program. In this issue, The Maryland describes Abilities Plus, its new automobile and homeowners insurance programs that were specifically designed for individuals with disabilities and their families.

We are pleased that the Abilities Plus program is sponsoring the distribution of Exceptional Parent at the Special Olympics World Summer Games. We look forward to meeting many of our readers at the Games and joining them in cheering for the athletes and volunteers from throughout the world.



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#### LETTERS

#### **Mental Retardation?**

Last week, I picked up a copy of *Exceptional Parent* at my son's school. As I glanced through the magazine, the words "mental retardation" stood out on a page in the Exceptional Parent Library listings. I found this phrase to be very offensive.

I have a child who is both physically and mentally impaired. "Impaired" seems to be a very accepted word and sounds much nicer than "retarded." I think the editors should consider this and change this category of books to "Mental Impairment." I know this would make the magazine more appealing to me.

K.S., Michigan

EDITOR'S NOTE: There are no uniformly acceptable terms for many kinds of disabilities. Foremost, however, we are advocates of using "people first" language—that is, always referring first to the child or adult, then to the disability (for example, "a child with epilepsy," not "an epileptic child." In keeping with this perspective, we do not use "disabled" or "retarded" or "impaired" as a noun (such as referring to "the needs of the disabled"). I always try to speak this way as well, even though it can sound awkward at times.

I prefer to use the term "mental retardation," rather than "mental impairment," because it is important to make a clear distinction that mental retardation and mental illness are two different disabilities. The term "mental impairment" does not make this distinction clear. While some people have both mental retardation and mental illness, most people with mental retardation are not mentally ill. Similarly, most people with mental illness are not mentally retarded. People with both disabilities have suffered because the general public lacks information about this distinction.

There are also some parents and

professionals who do not believe we should use any labels—believing that any label can lead to discrimination. Sa'ly, that is sometimes true. However, I believe that "labels" can also lead to greater understanding of individual differences, and can help family members and people with disabilities connect with one another.

—S.D.K.

#### Epilepsy—Ketogenic Diet

I'm writing to express my disappointment in the March 1995 issue of *Exceptional Parent*, which focused so much attention on epilepsy without even mentioning the ketogenic diet.

Our three-year-old son, Ben, began having seizures at 10 months of age. These were diagnosed as infantile spasms. Even after two courses of ACTH (adrenocorticotropic hormone) and trials of every anticonvulsant in every possible combination, Ben's seizures continued to worsen.

continued on page 8

#### EXCEPTIONAL PARENT

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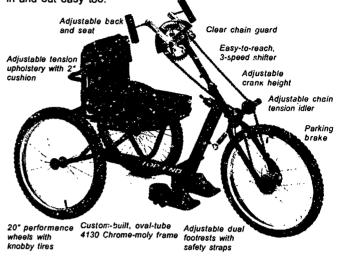
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continued from page 4

He was finally diagnosed with Lennox-Gestaut syndrome.

Ben experienced tonic, tonicclonic, atonic (drop attack), myoclonic and atypical absence seizures—more than 100 seizures every day. His EEG (electroencephalogram) was profoundly abnormal. Ben was also becoming increasingly withdrawn, lethargic and delayed, and was developing many autistic-like behaviors.

The doctors held out little hope of ever getting our child's seizures under control. Through a friend—one I made as the result of a *Search* letter—we heard of the ketogenic diet. Having no other course of treat-

ment left to try, we decided to investigate it.

On November 1, 1994, our son was admitted to the hospital and placed on the ketogenic diet. Within two weeks, he was seizure-free and off all his medications. On February 21, 1995, Ben had an EEG—and the results were normal! Even his neurologists were amazed.

It's been more than six months since Ben's last seizure and I feel I must share this with others. We are very fortunate that this treatment was available to us, and I know there must be other children who may benefit from this diet.

Ben is still quite delayed, but is making steady progress. Most importantly, he is happy and safe. That's all we ever wanted, really. The ketogenic diet was the light at the end of a very long, dark tunnel.

D.S., New York

EDITOR'S NOTE: The Epilepsy
Foundation of America (EFA)
stresses that the ketogenic diet—a
very restrictive high-fat, low-protein
and -carbohydrate regimen—is in
no way a "do-it-yourself" treatment.
The dict must be initiated in a hospital setting under medical supervision and followed strictly thereafter,
with frequent medical checkups.
EFA notes that following the diet
requires a truly dedicated team of
health professionals and family
members.

The Johns Hopkins Ketogenic Diet Factsheet explains that the diet has typically been used with children who have uncontrolled myoclonic, atonic and tonic-clonic seizures. Some studies suggest it is less effective for partial or focal seizures, or for absence or petit mal scizures. However, it is impossible to predict which children will experience seizure control with the diet; many studies suggest that more than 50 percent of children with ancontrolled seizures will be helped considerably.

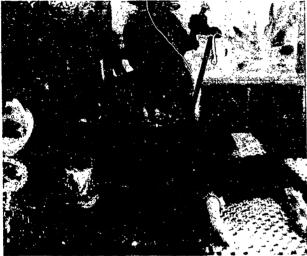
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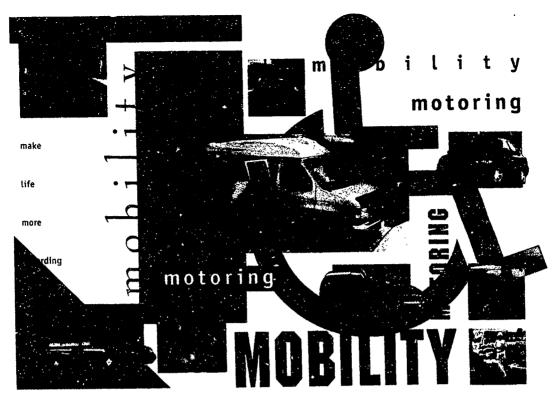
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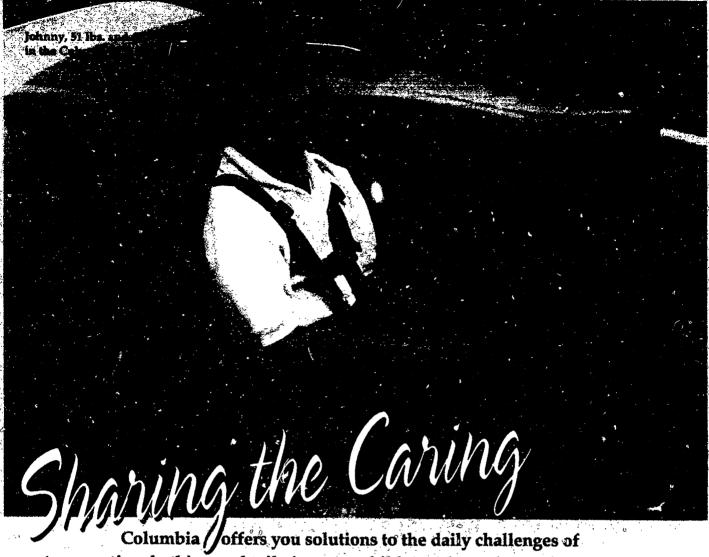
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Wrap-Around

continued from page 8

The diet is used most often with children aged two to six. It is difficult to implement and maintain in children younger than two, while children older than six often rebel at its restrictions. The diet is typically continued for at least three years.

For more information, EFA recommends the following resources:

- THE EPILEPSY DIET TREATMENT: AN INTRODUCTION TO THE KETOGENIC DIET (paperback, 1994, 180 pp.): Written by medical professionals at Johns Hopkins; Demos Publications, 386 Park Ave. S., Ste. 201, New York, NY 10016; (800) 532-8663; \$21.95.
- AN INTRODUCTION TO THE KETOGENIC DIET: A TREATMENT FOR PEDIATRIC EPILEPSY (video, 45 min.): The Charlie Foundation, 1223 Wilshire Blvd, Box 815, Santa Monica, CA 90403; free (send card with name and address).
- The Johns Hopkins Ketogenic Diet FACT SHEET (factsheet, 4 pp.): The Epilepsy Foundation of America, 4351 Garden City Dr., Landover, MD 20785-2267, (800) 332-1000; free.

#### **More Vacation Memories**

We just received our April 1995 issue and were happy to see Mickey Mouse on the cover, but not so happy that we didn't get our vacation story and snapshots off to you in time. We ended up with too many appointments in February and missed the deadline. If you could run this letter with Bryant's picture I know he'd be so happy!

We have been to Disney World three times and are planning to go again. Bryant's 180-pound power wheelchair makes flying difficult, so we drive. We pack up all his supplies, which can be quite a trick! He eats by g-tube, and one trip means about three cases of Pediasure. Bryant has a tracheostomy and needs humidity at night, so we also need to bring his compressor and humidity "collar."

Anyway, if we could say anything to other readers, it would be this: Go to Disney World if you've got the chance! Bryant spent three years on

life support and could not leave our house except for medical emergencies-unfortunately, those were plentiful. But now that life has stabilized, we enjoy every possible moment.

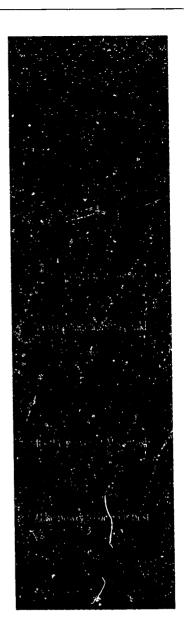
Of course, there is more to life than Disney World, but the feeling we get from going there and the way the Disney people handle kids with special needs is beyond any place we've ever seen. They have gone out of their way for us and for Bryant each time we've visited. We have met Disney characters-including Snow White, Peter Pan and Alice-in-Wonderland-at a Disney character breakfast. Later on, they remembered Bryant by name and came over to greet him during the parade! I could go on and on-and wish I had done so for the vacation issue.

It's an incredible feeling to watch a child who had been critically ill having the time of his life. If you can see your way clear to go, it's worth the trip! Make sure you write to Disney first and explain your family's special needs. They will accommodate youespecially at the on-site hotels--and will make every effort to make your child's visit special.

I don't work for Disney, really! Cheryl Paquette, New Hampshire



Dave Paquette and children Bryant, 6, and Emily, 3, enjoy meeting Winnie the Pooh during a trip to Disney World.





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# PEOPLE WITH SPECIAL NEEDS HAVE SPECIAL AUTO INSURANCE NEEDS

anet was on the way to a physical therapy appointment with her son, Matt, when suddenly, another car ran a stop sign and... C-R-A-S-H! Fortunately, Janet and Matt escaped unharmed, but their van was damaged and undriveable.

When the tow truck arrived, another nightmare was just beginning. How would Janet get Matt up into the tow truck? Even if she could, would he be safe? What would she do with Matt's power wheelchair?

Then there was the question of the damaged van. Was her adapted vehicle properly insured? Would she be able to rent another accessible van while hers was being fixed? And

would her insurance policy cover the additional cost?

What would you do?
What would you do if you were out with a child who uses a wheelchair and your vehicle broke down?
Would your insurance company pay for the additional cost for special transportation to get you and your child home?

What would you do if your vehicle were damaged in a collision?
Would your insurance company cover the cost of repairing the special adaptive equipment you've added? Is

your insurance company even aware of the equipment you've added?

Would your insurance cover the higher cost of renting an accessible vehicle if your car or van were in an accident and needed to be in the repair shop for a few days? Or a few weeks?



Enjoying a summer outing are (clockwise from left) Rob, Laura, Jeff and David Glushakow. Laura spends much of her spare time transporting Jeff and David to sports practices, art classes and other extracurricular activities in the family's adapted van. "If our van were stolen or in an accident and had to be repaired, our lives would come to a virtual standstill," she says.

#### Could this happen to you?

Linda is a busy mother who lives in Baltimore, Maryland with her husband, Dennis, 19-year-old son, Tony, and 15-year-old daughter, Tina, who uses a power wheelchair. When Tina isn't studying, racing, playing basketball or swimming, she and her mother are often on the road, traveling to and from Philadelphia, where Tina sees a number of doctors and therapists.

"I worry about what we would do if our van broke down," admits Linda. "How would I get help? And what would Tina do? I guess we would just have to get out, and walk and roll to a phone."

A company that cares about special needs

Most insurance companies don't realize that some of their customers have special needs. Or they don't want to think about special needs—because that would mean spending a lot of time, effort and money designing entirely new programs for a small percentage of their customers.

"The Maryland Insurance Group is the first corporate sponsor of a Special Olympics Family Program at the state level in the United States, as they are now the sponsor of the Maryland Special Olympics Family Program. With the "ABILITED PLUS" program, and their close involvement with families in Special Olympics, the Maryland Insurance Group has certainly taken a leadership role in providing exceptional caring services to families with special needs children."

—Jim Santos, Family Director Special Olympics International

Most insurance companies develop policies, then search for people to buy them. The majority of their customers have typical abilities and needs. But what about the millions of people in the United States today who have some type of disability? And what about the people who care for them or transport them? Who has addressed their needs?

No one. Until now.

The Maryland developed Abilities Pills, not because the law requires them to (it doesn't), but because they care and it's the right thing to do.

At The Maryland, they have not only thought about people with disabilities, they have spent the last two years talking with men, women, teenagers and children throughout the United States, finding out what customers with special needs want and need. Now they've designed an insurance program to meet those needs. They call this program Abilities Plus.

#### Could this happen to you?

Helene and Jack, a California couple, are facing a dilemma. "Like all of her friends, our 18-year-old daughter, Beth, wants to get her driver's license—and we don't blame her. But frankly, we've been avoiding the subject," says Helene. Beth has been using a manual wheelchair since a diving accident seven years ago left her a paraplegic.

"Who would insure her? Even if she could get coverage, the

### "ABILITIES Plus—what a phenomenal program! Light years ahead of your contemporaries—on the cutting edge!"

—Patricia McGill Smith, Executive Director National Parent Network on Disabilities

cost would probably be astronomical. We haven't even mentioned the possibility to our insurance company," Jack adds.

#### Could this happen to you?

"We are an extremely busy family," says Laura, who runs a household, works part-time outside of her home and, along with husband Rob, transports their two sons, Jeff and David, to baseball practice, art classes and a variety of other appointments and activities in the family's adapted van. Ten-year-old David, who has muscular dystrophy, uses an electric wheelchair.

"If our van were stolen or in an accident and had to be repaired, our lives would come to a virtual standstill. David and his wheelchair couldn't go anyplace," Laura says.

#### A company that listens

The Maryland has listened to the personal experiences, concerns and frustrations of hundreds of people with disabilities, their families, their caregivers and leaders of national organizations and associations. And in the process they discovered something very interesting—in addition to their special needs, safety and security are more important to people with disabilities than to most people. They pre-plan their travel, drive fewer miles and appear to have fewer accidents. They take good care of their homes and property, often equipping them with special safety features for added protection. And they are more likely to follow manufacturer recommendations for regularly scheduled vehicle maintenance.

### The Maryland wants to change cutomers' traditional perception of insurance companies.

Think for a moment. When was the last time an insurance company offered you a program or service *designed especially for you*—a program that takes into account that you or someone you love has a disability?

When was the last time an insurance company sought out your business and promised to work with you to further develop and enhance their coverages and services to neet your needs, now and in the future?

continued on page 20

"ABILITIES PLUS targets a previously ignored market of people with disabilities and their families who can benefit from having protection or security from the financial hazards associated with auto travel—a significant aspect of our liberty!"

—John D. Kemp, Executive Director United Cerebral Palsy Associations

### THE MAN BEHIND THE SCENES... Patrick Favale

Director, Anumes Plus Program

n Christmas Eve, 1969, Patrick A. Favale, a Sergeant in the U.S. Army, was critically wounded in Vietnam. He spent the next 11 months in the hospital, recovering and adjusting to his injuries. In addition to receiving a Purple Heart, Pat was twice decorated. Although his wounds left him with a disability, Pat went on to marry and ralse a family. He has spent the past 18 years working in the insurance industry, where he has met with great success.

Two years ago, Pat was given the special assignment of answering this question: What if The Maryland were to develop a program that would specifically meet the needs of people with disabilities? "I considered it a privilege to be put in charge of such an important project," Pat says. "What made this so special is that this was the first time in my career that I've been able to integrate 25 years of experience as a person with a disability and 18 years as an insurance professional to help others in the disability community."

Pat began with an exhaustive search for information about people with disabilities in relation to the insurance industry. He found very little. Pat recalls, "I did find out one thing. Everyone told me I was the

first person from an auto and homeowner insurance company to ever ask about the special needs of people with disabilities and those who care for them." Pat realized that the only way he was going to gain a better understanding of individuals' special needs was to go out and meet people personally. And that's exactly what he did.

For the past two years, Pat has traveled thousands of miles across the country, has attended numerous meetings and conferences and has talked with hundreds of people with disabilities, family members, caregivers and leaders of national organizations. Early on, working with the Maryland Special Olympics and conducting a survey of the National Amputee Golf Association gave Pat an appreciation of the lifestyles, obstacles, frustrations, needs and concerns of individuals with a range of disabilities.

As a result of the information Pat gathered, The Maryland created ABILITIES PLUS, the first automobile and homeowners insurance program that addresses—rather than ignores—the needs of people with disabilities. Reflecting on two very busy years, Pat says, "During the last two years, my life has been enriched beyond measure. I have had the privilege and pleasure of meeting the most incredible and inspirational group of people one could ever hope to meet in a lifetime. And even though this was a very challenging time for me, my project team and the company, it was time well spent—because the vision we had two years ago is now a reality."

Pat is much more than an insurance professional; he's an advocate. "People with disabilities are currently underserved in many areas, especially insurance," he says. "The Abilities Plus program has the potential to revolutionize the automobile and homeowner insurance industry and finally give people with disabilities and those that care for them the coverage and services they need... and the peace of mind they deserve."



Pat Favale (right). shown here with wife Barbara and twin sons David and Jason, 19, says that developing the ABILITIES PLUS program was one of the highlights of his professional career. "This was the first time in my career that I've been able to integrate 25 years of experience as a person with a disability and 18 years as an insurance professional to help others in the disability com-

munity," Pat says.



1.16



# The tow truck is here. Now

How do I get my son home safely?

Abilities Plus takes care of your vehicle and your son. It reimburses you, up to a dollar limit, for the cost of the special transportation be needs, too.

Is my van properly insured?

Abilities Plus also expands your coverage so that your vehicle, with its special modifications, can be repaired.

How do I get another van?

You can rent the kind of replacement vehicle you need, because *Abilities Plus* doesn't restrict you to a daily dollar limit like most policies. Instead, it provides an aggregate benefit which gives you greater flexibility.

ERIC



# what?

Abilities Plus is comprehensive insurance for people with special needs. It's Roadside Assistance, access to a dependent care network, and many other services that add value for our customers.

It's also fast, fair claim settlement, and customer service that's available whenever you we seak with someone,

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# Abilities PLUS

Caring for your special needs.

Circle #131

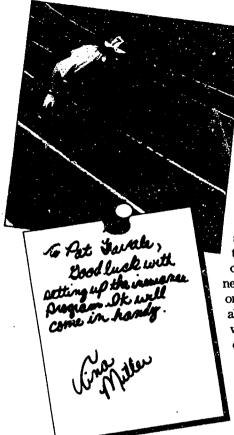
# The Maryland Personal Insurance

.....

A member of the worldwide ( Zurich Insurance Group

Coverage availability varies by state.





When was the last time an insurance company asked you if you had the right kind of coverage for your vehicle and home—and any special equipment or adaptations?

And when was the last time an insurance company made you feel welcomed?

The Maryland is a caring company committed to developing a better understanding of its customers and to continually meeting their changing needs. You don't need to withhold information or hide a family member's disability—because Abilities Plus was designed especially for children and adults with disabilities and those who care for them.

### What exactly is Abilities Plus?

On one level, ABILITIES

PLUS is unique coverage designed especially for you and the people you care for. On another level, it's comprehensive automobile and home insurance at a competitive price. It provides outstanding customer service and rapid, fair claims settlement—the kind of service you should expect from any insurance company.

- Tailored Auto Protection: When you purchase your basic policy from The Maryland you can choose the additional coverages you need from the ABILITIES PLUS program. ABILITIES PLUS was created for people who use wheelchairs and have modified vehicles, and those who have other special needs that require different types of coverage than those offered by other insurance companies.
- Special Towing and Labor Coverage: If your vehicle is in an accident or breaks down and must be towed, this enhanced benefit reimburses you up to \$75 per breakdown for the cost of special transportation needed for the person with a disability.
- Special Extended Transportation Coverage: If your

"The Abilities Plus program offered by The Maryland is a significant step... and few businesses have recognized the opportunity to market specialized programs. I applaud The Maryland's initiative."

-Kent Waldrop, Founder and President Kent Waldrop National Paralysis Foundation

"The ABILITIES PLUS program recognizes the unique needs of people with disabilities, and by providing for such needs, gives [them] their equal status in society."

---Ross Catalano, Executive Director National Association of People with Disabilities

vehicle is involved in an accident and needs to be repaired, ABILITIES PLUS offers coverage that gives you greater financial flexibility to rent a vehicle with the special equipment you need—more dollars per day toward the rental cost of a replacement vehicle.

• Special Customized Equipment Coverage: The higher cost of repairing or replacing your modified vehicle can be covered under ABILITIES PLUS.

### The Maryland doesn't want to meet your expectations; it wants to exceed them.

That's why their offices are staffed 24 hours a day, 365 days a year. When you call, you'll speak with a person, not a machine, a patient, competent person who will respond to your questions and problems with understanding and sensitivity.

The professionals at ABILITIES PLUS have two goals in mind—to get you back into your car or home safely and help you get your life back to normal as quickly as possible.

"ABILITIES Plus mirrors the mission of Special Olympics' 27-year history—the empowerment of people... This insurance product uniquely addresses the underserved needs of families and people with disabilities.

"The ongoing commitment of The Maryland Insurance Group to the community with disabilities is not simply evidenced in this product. Maryland Special Olympics is proud to recognize their commitment to our local program as well as... financial support, leadership and employee volunteer participation.

"This is clearly a marriage of enormous corporate citizenship tied to a product whose time has surely come."

—Patricia Krebs, Ph.D., CEO Special Olympics of Maryland

#### More for your money

ABILITIES Plus also offers you these value-added services:

- Floadside Assistance: 16,000 garages throughout the country are ready to assist Abilities Plus customers at special reduced rates.
- Guaranteed Auto Repairs: To make sure you get the best claim repair service possible, Abilities Plus has organized a network of auto repair facilities whose work is guaranteed for as long as you own your vehicle.
- Dependent Care Network: If you need to be away from home for a few hours or overnight, as an Abilities Plus customer you can get a referral to qualified help at a spe-

cial discount. One toll-free phone call is all it takes to get a homemaker, personal care assistant or other home health professional.

 Information about Disabilities: How do you find out about specific disabilities and support groups? Where can you learn about the availability of vocational training programs for young adults with



Tina Miller, 15, shown here with parents Linda and Dennis, and brother Tony, 19, is a typical active teen. Along with her participation in a variety of sports, Tina and her mom spend a lot of the time on the road, traveling back and forth from their Baltimore home to appointments with medical specialists in Philadelphia. "I wony about what we would do if our van broke down," admits Linda. "How would! get help? And what would Tina do?"

disabilities?
How can you
get information on assistive technology?
Access to a
wide range of
information
resources is only
a toll-free phone
call away.

- Mail Service Pharmacy: You get reduced rates on brand-name or generic mail-order drugs for the treatment of chronic illnesses or conditions.
- Telephone Calling Card: A discounted phone card saves you money on long-distance credit card calls.

### A commitment to future development

At present, ABILITIES
FIL'S may not be able
to meet everyone's
special needs. But
The Maryland is com-

mitted to the continued development and enhancement of ABILITIES PLUS via direct input from people within the disability community. The Maryland looks forward to hearing from you so ABILITIES PLUS can continue to expand its capabilities—caring for your special needs.

"The first of its kind... needed by thousands... your company is a champion of people with disabilities."

-Nita Savader, Ph.D., Executive Director Association for Special Kids. Inc.

We can't end discrimination against people with disabilities, or change the physical environment. But Abilities Plus can make everyday life a little easier, safer and more comfortable.

To get more information or to ask for free quotes on your automobile and home insurance, call The Maryland

at 1-800-222-2788, or mail in the postage paid reply card provided. You can also write: c/o Patrick A. Favale, ABILITIES PLUS, P.O. Box 1228, Baltimore, MD 21203-1228 and tell him what you think about the program and about your special needs.

If this program doesn't apply to you, maybe you know someone who could benefit—a friend, a relative or an organization. Won't you pass this information along so ABILITIES PLUS can provide quality coverage and service for the people who can use them the most?

## Frequently Asked Questions About Abulties Plus

- Q. Who is eligible for the Asiumes Plus Program?
- A People with disabilities.
  - · People who care for family members who have a disability.
  - Employees of human service organizations who use their private vehicles to transport people with disabilities.
- Q. I already have car insurance. Won't that cover any damage my modified van would sustain in an accident?
- At Not necessarily. Check your policy. If you've added adaptive equipment, such as a wheelchair lift, raised roof or customized control devices, your insurance company isn't obligated to cover the cost of fixing or replacing them unless they are properly covered under your policy.
- Q. What's the difference between my current auto policy and ABILMES PLUS if my vehicle breaks down?
- ABILITIES Plus can guarantee to reimburse you up to \$75 toward the cost of special transportation needed to get you and the person with a disability to a safe place any time your vehicle breaks down away from home.
- Q. Is the program reasonably priced?
- As You may be surprised how reasonable the cost is. Why not call the toil-free number and ask for your no-obligation automobile and homeowner quotes?
- Q. is Asiumes Plus available in my state?
- A: Coverage availability varies by state. We are continuing to add additional states each month.

Even if ABILITIES Plus is not yet available in your state, we are eager to hear from you and every other interested consumer for three reasons:

- 1. We want to send you information about ABILITIES PLUS.
- 2. We want input about ABLITIES PLUS from consumers everywhere. We want to meet your insurance needs and find new ways to serve you.
- We want to be able to contact you when Asiums Plus becomes available in your state.
- Are there any special requirements to apply for Ammes Plus?

  A: No. Just call 1-800-222-2788 or mail in the postage paid reply card

provided. You can also write: c/o Patrick A. Favale, Abumes Plus, P.O. Box 1228, Baltimore, MD 21203-1228 and share your thoughts.



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#### LETTERS

continued from page 15

#### **Definitions. Please!**

I have been receiving your magazine for about one year and find many of the articles helpful and interesting. I even initiated a "Search" letter which received a few responses.

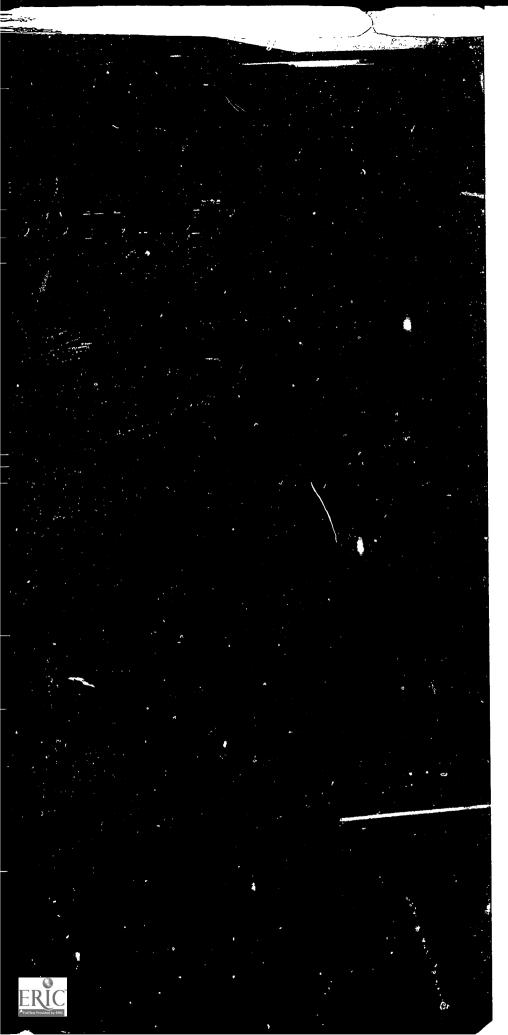
However, I have one suggestion which I am sure many other readers would also appreciate. The articles and departments—especially Search and Respond-contain many names of specific conditions or other words that are unfamiliar to those of us who have children with other disabilities. It would be helpful to have some kind of glossary at the end of the magazine in which these terms could be defined.

I noticed that in the April 1995 issue some definitions were given. usually in parentheses after the name of the condition, and that the Ask the Doctor column provided excellent definitions for conditions and medications. I found this very helpful in visualizing the situation that was described. I would like to see more of this throughout the magazine.

Your magazine has provided me with some valuable information and I have recommended it to several other parents of children with disabilities. Keep up the good work!

M.S., California

EDITOR'S NOTE: We're glad you've d our recent attempts to provide definitions for specialized terms. These efforts continue with this issue and we would appreciate reader feedback on how we are doing. Rather than a glossary, we are attempting to define terms within the context of their appearance or, in some cases, with a sidebar (as in this issue's Fathers' Voices). We appreciate when people writing SEARCH and RESPOND letters provide definitions of the terms they use; this can save us the time it would take to obtakn this information from other sourdes.



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Our athletic sport pakoffers water bottle space with high sides for easy access will our front pouch also for quick hand entry to kays, wallets or gloves. Able Disabled Athletes love this beg.\ For fit and convinience

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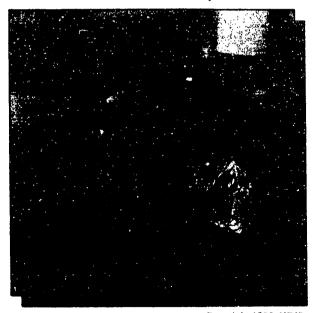
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# SEARCH

#### Chromosome 14q+

I am a parent of a seven-year-old boy who has been diagnosed with the chromosomal abnormality 14q+ (the addition of chromosomal material to the long arm of chromosome 14). The origin of the additional chromosomal material has not yet been identified. James was born with a low birth weight, a club foot, an eye syndrome and microcephaly (a small head). The doctors told me James would probably be developmentally delayed.

James' growth rate has been slow. He has nighttime feedings through a gtube. He is on a strict feeding program to encourage him to take more food by mouth. His development has been slow, but he progresses steadily.

I would like to know if there is another child, somewhere in the world, who has the same chromosomal abnormality or any of the same symptoms.

R.B., Ontario, Canada

#### Alpers Disease

My 20-month-old daughter, Kristin, has been diagnosed with Alpers disease, or progressive infantile poliodystrophy, a terminal illness. I am searching for another parent or family with a child with this disease.

M.A., Georgia

#### Foix-Chavany-Marie Syndrome

My son, Austin, is five years old. Last summer, he was diagnosed with a rare disorder called Foix-Chavany-Marie syndrome. Some of the nallmarks of this syndrome are mild mental retardation, poor motor skills, no speech and a pleasant personality.

Austin has developmental dyspraxia (difficulty with planning and performing coordinated movements), low muscle tone, poor gross and fine motor skills and no speech. He does vocalize and uses sign language to communicate. Due to his fine motor difficulties,

Austin's signing is not exact. We are trying to get funding for an augmentative communication device.

We want to find other children or adults who have the same problems as our child.

J.B., Kansas

#### Tell us about...

... your child's favorite toy or playtime activity. (Have you found ways to adapt toys or play activities so your child can participate more easily?)

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.



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ment the same way as a human ear, by continually balancing ambient noise with more specific sounds, allowing your child to identify important, even critical, sounds—like your voice. Don't let your child be cut off from his or her surroundings... Sennheiser supplies the freedom to connect.





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Circle #224

. 0 8

#### Feeling Isolated

Our four-year-old daughter, Katie, has been diagnosed as having pervasive developmental disorder (PDD), or developmental delays with autistic characteristics. We first became suspicious that something was wrong when she was about 18 months old. Before that age, although she never spoke any words, she babbled. She waved and pointed and played a little with toys. She would go get her diapers when we asked. Her eye contact was normal.

But by two years of age, she had stopped making sounds and had developed an awful temper. She would gather up toys and then just walk around endlessly holding them. She would let us hold her, but she was just as happy to be alone.

An EEG, CT scan and hearing tests were normal.

Katie's eye contact continues to improve and she is again very lov-

able. She smiles and laughs a lot. She loves to be with her brother and other children. However, she still doesn't talk. She signs "eat" and "more." We have a communication book, but she doesn't use it. She slaps her chin when she wants to communicate. Sometimes these slaps are soft and teasing, but when she's frustrated, she slaps pretty hard.

Katie continues to have hardly any interest in toys. She just picks them up and drops them. Her motor skills are a little delayed and she is just now starting to use utensils with help. When Katie is anxious or tired, she alternates loud and heavy breathing with holding her breath. Potty training is just not coming, either. She wants to eat constantly!

Katie seems to understand so much more than she can tell us. She may not get her shoes when asked, but we'll catch her glance at them. In fact, she often glances casually at what we are talking about.

We live in a rural area and our school is helping as much as they are allowed to, but that help isn't consistent enough. Does anyone have a child like Katie? We are at the end of our rope. We feel so strongly that with more help, Katie could do so much more; we are just so alone.

K.H. & E.H., Idaho

#### Undiagnosed

After a variety of genetic tests by a wonderful team of medical professionals, our 21-month-old son remains undiagnosed. I can't imagine our child is the only one out there with the following birth defects. He was born eight weeks premature but was large for his gestational age (five and a half pounds). An amniocentesis had revealed kidney problems, but no chromosomal abnormalities.

continued on page 30



# Transport your child safely & securely

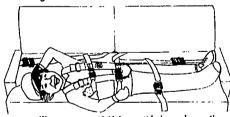
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ولا أو الله

continued from page 29

Immediately after birth, Clifford was diagnosed with the following conditions right hydronephrosis with reflux (an obstruction of the urethra in which urine flows backward, from the bladder to the pelvis, causing pelvic swelling) and pseudo-prune belly syndrome (having the appearance of prune belly syndrome, a condition in which abdominal musculature is missing and the urinary tract is malformed),

an abnormal aortic cardiac valve, cataracts, high palate and brain anomalies (decreased volume of cerebellum and thin corpus callosum). Clifford could not be weaned off the respirator in the NICU but when taken off with do-not-resuscitate orders, he amazingly, figured out how to breathe. A poor suck/swallow reflex necessitated gastrostomy tube placement.

At 21 months, Clifford is off the g-

tube, but has many developmental delays, poor muscle tone, no eyebrows, hearing loss due to atresia (absence) of the ear canals, very limited weak vocalizations due to a seriously narrowed trachea and dysmorphic facial features. Constant congestion affects his daily breathing and sleeping. In spite of daily antibiotic use, doctors say Clifford's sinus and ear cavities are totally infected. He will probably need surgeries for these infections.

Doctors have done various blood studies and a skin biopsy. They have ruled out G syndrome, Zellweger syndrome, Prader-Willi syndrome and Pallister-Killian syndrome. Next, Clifford's blood will be tested for Smith-Lemli-Opitz syndrome. I do not feel that he has enough of the characteristics of this syndrome but we will follow through with the blood test.

We read *Exceptional Parent* religiously in hopes of finding a child similar to our son. The original prognosis was for a child with severe retardation and medical impairment, if Clifford survived at all. However, each of Clifford's impaired organs has shown remarkable improvement, and tests show his brain is processing speech. We now face a very uncertain future and would appreciate any helpful information.

B.C. & C.C., New York

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

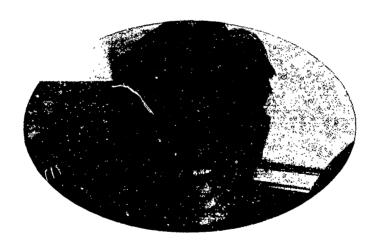
Write or fax:
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Exceptional Parent
209 Harvard Street, Suite 303,
Brookline, MA 02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in EXCEPTIONAL PARENT'S 1995 Resource Guide (January 1995).



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inconvenience of bed-wetting with protection from GOODNITES® Absorbent Underpants.

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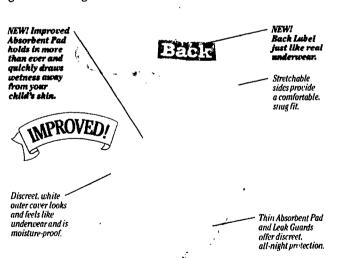
GOODNITES Absorbent Underpants feel better about themselves and that makes for better mornings for everyone.

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- Watch what your child drinks Limit liquids after dinner Drink water, not juice or soda
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# 5

### A Great Scouting Opport

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County, CA, is just like any other boy scout troop, second from most of the boys use wheelchairs, their particles are traditional scouting activities is a major challenge one they face with pride and determination. The stoop founded by Bruce Marich, president of Southess.
California Mobility, is currently raising money to the print-bus equipped with a Ricon lift.

Uptil then, Bruce's personal vair installed with the Ricon's \$4231 Clearway Whedistrair Lift is ideal for the troop's transportation needs. Its strong steel frame and powerful hydraulic pump provide a fast, secure means of entry and exit for the spouts. And the fully automatic split platform of the Clearway lift folds up and out of the way, leaving the doorway clear for loading and unleading supplies.

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## R-ESPOND

#### **Therapeutic Recreation**

E.W. (December, 1994) hopes to establish a community recreation program that includes children with disabilities. Specifically, he wanted to know how established programs of this type were operated and funded.

I suggest you contact the National Recreation & Park Association. Specifically, you should contact this special-interest section: National Therapeutic Recreation Society (NTRS), 2775 South Quincy St., Ste, 300, Arlington, VA 22206; (703) 820-4940, (703) 671-6772, fax.

The folks at NTRS should be able to advise you and put you in contact with existing programs in your area. Good luck!

D.V., Oregon

Early Myoclonic Encephalopathy M.D. (October, 1993) wrote about her then six-month-old son, Austin, who

has early myoclonic encephalopathy (EME), a rare seizure disorder. Austin was conceived while his parents were using the contraceptive sponge with Nonoxynol-9 spermicide. M.D. was hoping to find more information about EME and other parents with whom to correspond.

I originally wrote to you, enclosing my address and phone number, soon after your *Search* letter appeared in *Exceptional Parent*. As fate would have it, you called me the day of my son's funeral. That must have been horrible for you. But for some reason, I feel closer to you because of it and I would really like to get to know you. I know you also sent me a letter, but I was like a zombie for a few months after my son's death, and now I can't find your address.

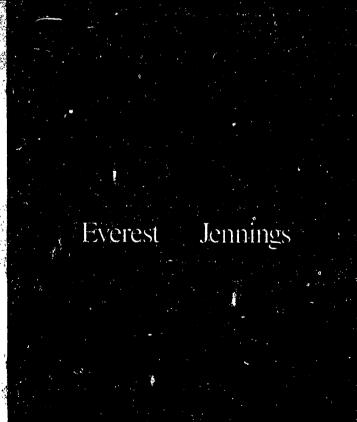
Our lives have changed a lot in the last year. When Danny passed away in May, I was pregnant. Our son, Charlie, was born in September, 1994.

Last January, I landed a job as service coordinator for the Arizona Early Intervention Program. Several agencies wanted to hire me because of my "service coordinator" experience with Danny. At the time, I had no idea I was being a service coordinator, all I knew was that my son needed equipment, medical supplies, home nursing care and more. I found that I was more effective than our case manager in getting reimbursement approvals, so I did my own legwork.

At one point, I had approval for inhome nursing and desperately needed the help, but there were no state-contracted nursing registries that would provide a nurse for more than two hours at a stretch. So I recruited a different nurses' registry to contract with the state so I could have a nurse. I didn't know this was service coordination—I thought it was survival.

continued on page 38

park, and pondered the panthers and pythons, then probed along the surface of Mars in their trusty all-terrain vehicles. They've recovered the last of the golden keys while their computer proclaims them heirs to the realm. Kid PowerTM is for kids making tracks. A child's tool, like a child's toy must be durable and adaptable, allowing them the freedom and range to explore their environment creatively and independently. Kid PowerTM is tough and reliable with a unique styling that adjusts to your child's changing needs. Kid PowerTM is easy to program, with precision controls, accessible battery boxes, controlled tracking, a rugged steel frame and a host of options that allow kids to assert their individuality and lifestyle.



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Circle #62

#### RESPOND

continued from page 36

Another time, Danny needed respiratory treatments every two hours around the clock. I made it through 48 hours before I talked the insurance company into paying for inhome treatments and talked the respiratory therapists at the local hospital into doing the in-home work. Survival—not necessity—is the mother of invention. I'm glad I learned so much from Danny. Now, I am able to share my knowledge and abilities with other families.

How is Austin doing? And how are you holding up? I am definitely recovering from the loss of Danny and I would like very much to get to know you and your family. I hope you feel comfortable writing to me; and if you call, I promise no strangers will answer my phone this time.

B.S., Arizona

EDITOR'S NOTE: SEARCH letters often receive responses months, even years, after publication. Readers who have had SEARCH letters published at any time should make sure EXCEPTIONAL PARENT'S editorial office (209 Harvard St., Ste. 303, Brookline, MA 02146) always has a current address to which we can send any responses we receive.

#### **Persistent ATNR**

T.W. (March 1995) has a 17-month-old son with cerebral palsy. Because of a very persistent asymmetrical tonic-neck reflex (ATNR), his right hand constantly digs into the side of his face. Someone has to hold his hand during play, therapy and feedings. T.W. wanted advice from others who have experienced this problem.

Over the years, I have taught several students whose abnormal reflexes caused them to hurt themselves or others. It is heart-wrenching to watch a child pull his own hair, gouge his ear or cheek, or bite through his lip when an abnormal reflex takes over. The child is caught in a vicious circle where the reflex causes pain which causes an increase in muscle tone, which strengthens the reflex, thus increasing the pain.

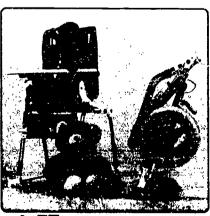
ATNR and bite reflex have caused the most trouble for my students. One of my students became a ball of nerves for fear that his out-of-control left hand would scratch his face, pull his hair or scratch his eye.

Here are four suggestions for dealing with ATNR: First, consult with your therapists about positioning. Don't be afraid to try what may seem to be unusual options. Different things work for different kids, even for those with similar patterns of movement. You should aim to reduce overall tone (the level of tension in nuscles at rest). What might seem like an uncomfortable position to you might be very soothing to your son if it frees him from his ATNR.

Second, try splinting. That's what worked for my student. His therapist and I used a small fabric knee immobilizer to keep his left elbow straight. He could choose to use the splint at any time—when he was playing, or doing artwork or schoolwork that excited him. The relief he felt at not having to worry about his hand translated into an overall reduction in tone. A word of caution, though—make sure all your son's caregivers understand the uses and limita-



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tions of splints. Splinting should be used only to enable the child, never to restrict the child or to reduce the amount of supervision he receives.

Third, I have seen various barriers used to keep the offending hand away from the head. Perhaps you could extend a padded barrier from your son's head rest, or over his shoulder from the back of a positioning chair. When he goes into an ATNR, his hand will press against padding instead of his head.

Finally, your reaction to the ATNR is important. If you become anxious and view the problem as a struggle, your son will imitate you. Anxiety raises tone and increases the probability of reflex. Explain the situation matter-of-factly to your son in a way that he can understand, and assure him that you and his therapists will find a way to help him control the reflex and avoid pain. During activities, be calm and positive. Give him the support he needs and focus on the task at hand, not on the ATNR.

C.H., Florida

EDITOR'S NOTE: Seating and positioning expert Elaine Trefler, M.Ed., OTR reviewed this response for EXCEPTIONAL PARENT. In addition to the many good suggestions from C.H., Elaine notes also that some children with ATNR may find it useful to tuck an arm under a wheelchair tray to keep it out of the way.

#### **Dandy-Walker Syndrome**

C.K. (April 1995) have a five-year-old son with a variant of Dandy-Walker syndrome. Doctors say C.K. and her husband carry recessive genes for this disorder. Since C.K. and her husband would like to have a second child, they wanted to hear from families who carry a recessive gene for this condition.

Sometimes, children are diagnosed with a variant of Dandy-Walker syndrome but really have Joubert syndrome. In the past, it could be difficult to differentiate the two conditions, however, this is changing as more research is done.

Joubert syndrome is genetically transmitted, and a decision about having more children is always difficult. We had a healthy baby girl after our older daughter was born with Joubert syndrome. I firmly believe that the decision about another pregnancy depends on what each couple thinks they can handle. They need to be pre-

pared for either possible outcome.

I am the founder of the Joubert Syndrome Parents-In-Touch Network (12348 Summer Meadow Rd., Rock, MI 49880; 906/359-4707). If you would like more information about Joubert syndrome or our organization, you can contact us.

M.V.D., Michigan

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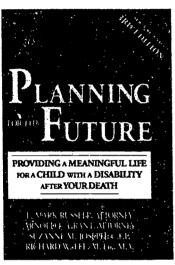
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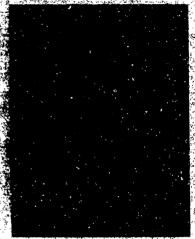
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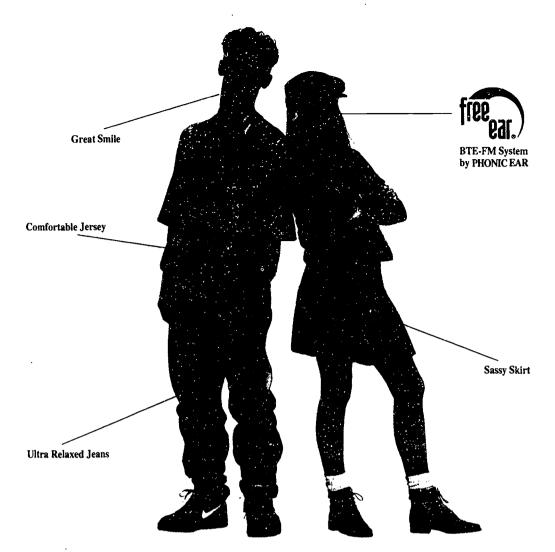
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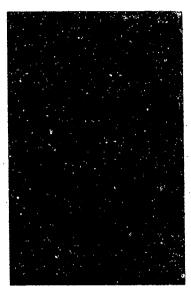
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### ramiliar races



Coming through! Three-yearold Rachel Ahrens shoots down a slide at the indoor playground at McDonald's, one of her very favorite hangouts. Rachel, who has low muscle tone, hip dysplasia and facial dysmorphia, is undiagnosed. She communicates using a combination of sign language, speech, an augmentative communication device, and, in this case, her broad smile. Rachel lives with her parents, David and Ginny, in Bemidji, Minnesota.

Chietopher Metcaif, 4, sports the cap of his home team—the Colorado Rockies. An avid baseball fan, four-year-old Christopher lives with his parents and big sister, Larissa, in Littleton, Colorado. Christopher has a low-grade astrocytoma brain tumor, and, due to a stroke, has left-side weakness and developmental delays. He attends an integrated preschool.



And now, coming down the track, in his third year of Soap Box Derby competition... it's Jeffrey Stewarti Jeffrey, 9, of Jamestown, New York races in one of four dualcontrolled cars purchased by the Masonic Blue Lodge, Chautaugua District, for use in the Special Olympian Division of the annual competition. Jeffrey, who has autism, loves participating each year and wears his souvenir T-shirt and helmet with pride.



€ 1/2 6

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Sulte 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!



Tiptoeing through the pages, Kayla Felicia-Marie Alialn doesn't let anything keep her from her favorite pastime—reading. Kayla, 18 months, was born without arms but has found that her feet work just as well. Better known as "Sunshine," Kayla lives in New Orleans, Louisiana.



Young horseinen Brien Crane is riding high on "Roz," his registered Shetland mere, led by 11-year-old brother, Mike. Brien, 4, has cerebral palsy, hydrocephalus and a seizure discretes. The family lives in Sheldon, Vermont.



# Opportunities for a Better Future

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The New England Center for Autism, is a community-based education center providing day and residential programs for students aged 3 to adult. Classes in communication, daily living, academics, employment and social skills are taught in 1:1 and low staff-to-student ratios. Our non-aversive approach is designed to bring children out of the severe isolation imposed by their disabilities and prepare them for productive, working lives in their own communities. The central educational facility of **The Center** is located just 20 minutes west of Boston, in Southboro, Massachusetts, with 13 attractive student homes in nearby communities. We are less than 3 hours from most eastern states and accept appropriate students from anywhere in the US.



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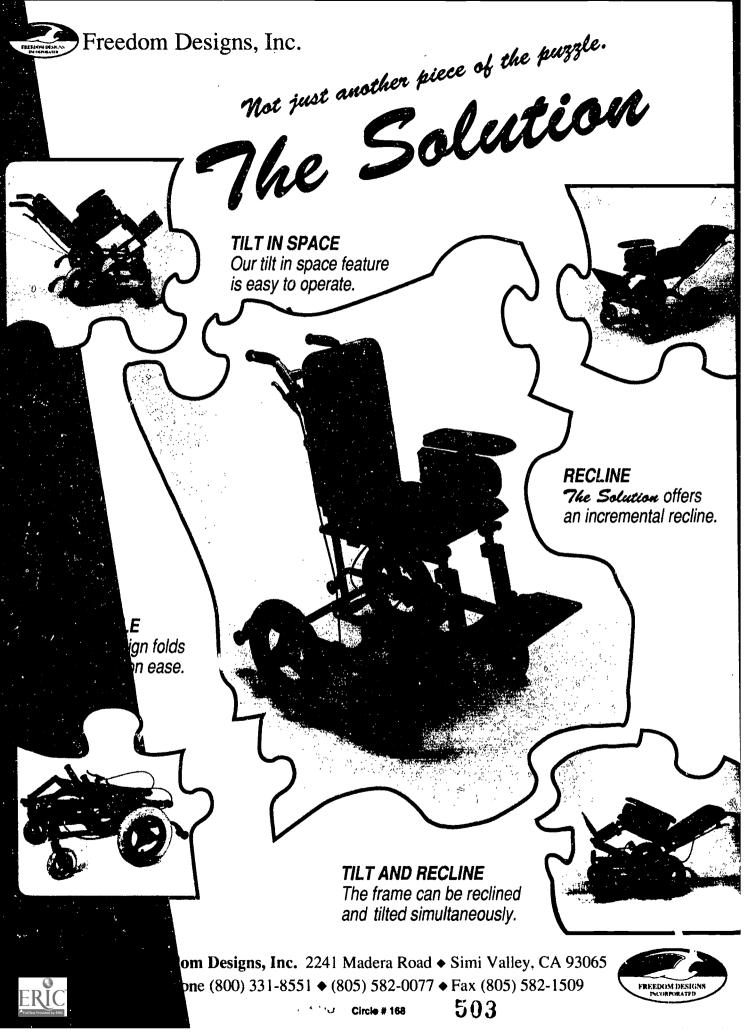


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# Fathers' Voices

# **Loving Sarah**

by David L. Parsons

part of me as breathing? I'm still reflecting on our life together as I pull into the same parking lot where I sat crying five

years earlier. I turn off the car, settle back and let the memories wash over me. I don't have to go looking for Sarah—I know I will hear her long before I see her...

After we dropped Sarah off, I sat in the car and cried. Actually, I sobbed. All of the frustration, anxiety, fear and love went through my body in one spasm after another. I remembered all the sleepless nights, doctors, hospitals, special diets, vomit and diarrhea. Then there were all the words I could hardly spell—hyperammonemia, wea cycle deficiency, ornithinc transcarbamylase.

But I also remembered all the tender moments with Sarah—her giggles and laughs, her teasing, her love and her courage.

After 20 years of living at home, Sarah was now enrolled in a residential school. I missed her already, and as tears poured down my face and old emotions swirled around me, a whole new set of fears jumped in—who would watch and protect her; check her diet, hold her hand, help her dress in the morning and kiss her good night?

n the familiar drive to pick Sarah up for a weekend visit home, I turn off the radio and roll down the windows on a beautiful September afternoon. I want to write about my life with Sarah, but how do I write about something that is as much a

### Life with Sarah

Sarah has a deficiency of a liver enzyme called omithine transcarbamylase (OTC) which is critical to protein metabolism. The condition is classified as an urea cycle disorder (see sidebar, page 50). By the time Sarah's condition was diagnosed, she had suffered irreparable brain damage.

Life with Sarah is much what it must be like to be a Siamese twin. She is all-consuming; her moods

affect my own. If Sarah tugs to the right, I have to follow; if I want to go to the left, I have to pull her along.

Small trips to the store can become major events. Sarah may get scared

and scream hysterically, or she may decide she wants a piece of candy and have a full-blown tantrum—sitting in the middle of an aisle and screaming at the top of her lungs.

Because Sarah is hyperactive, playtime usually becomes a constant state of turmoil. In trying to relate to other kids, she pokes, hits and aggravates others. Her friendly personality, however, must somehow pull her through because most kids develop a real

affection for her.

Sarah is one of the most loving people I know. She thrives on people, and plays hostess at most parties, introducing herself to everyone. In fact, she has a dynamic personality. You always know when Sarah is around.

Life with Sarah is full of emotions—often all mixed together at the same time—from love to hate, from panic to calm, and every-

thing in between. This dichotomy of emotion is symbolized by my two greatest fears—the first, that Sarah will die, and the second, that she will outlive Pam and me.



Sarah, 13 months, enjoys a wagon ride. By the time her condition was accurately diagnosed, at 18 months, irreparable brain damage had occurred.

### A joint effort

No part of my life escapes the effects of Sarah—family life, social life, business life, marriage and sex life. It has been a joint effort, with my wife, Pam, taking the brunt of it and the rest of us pitching in. For the family, it has been a shared sacrifice. Vacations were nonexistent when Sarah lived with us; even little things like movies

continued on page 50

Fathers' Voices is a regular feature of Exceptional Parent magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this when are encouraged.

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008. (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides network—gopportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.



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### More About Urea Cycle Disorders

A urea cycle disorder is one of six genetic disorders causing an enzyme deficiency in the urea cycle. The urea cycle is the body's way of breaking down excess protein into urea, which is eliminated from the body with urine. The urea cycle requires different enzymes, but when one of these enzymes is missing, it creates a blockage in the cycle that results in the build-up of ammonia in the blood. The highly toxic excess ammonia (known as hyperammonia) reaches the brain through the blood where it may cause irreversible brain damage and/or death.

One in every 25,000 children is affected by a urea cycle dlsorder. Many physicians believe there are many more cases, but

they are not properly diagnosed.

The effects of a urea cycle disorder usually do not appear until after the first 24 hours of life. At that point, the infant

becomes lethargic and begins vomiting. Soon after, seizures, decreased muscle tone, respiratory distress and coma may occur. Death generally occurs if no immediate intervention is taken to decrease the ammonia level. Cases where symptoms appear at later ages may be caused by a partial (rather than total) enzyme deficiency.

Treatment, individualized for each child, generally consists of a low-protein diet and the use of medications which provide ammonia removal. Prompt treatment may prevent brain damage and/or death.

This information was provided by the National Urea Cycle Disorders Foundation, P.O. Box 32, Sayreville, NJ 08872, (800) 386-8233.

continued from page 48

were few and far between.

But I have watched my other kids grow up with a strong sense of moral and emotional strength. Living through crisis after crisis teaches priorities.

Our marriage has come close to the breaking point more than once. It was hard enough when Pam gave birth to twins-Sarah and her brother, Michael, But Sarah's disease was truly traumatic. She had lapsed into comas twice by the time she was 18 months old. She couldn't sleep and would

thrash and cry all night long.

The doctors were brutal on Pam, telling us that Sarah's problems were the result of some sort of psychological mother-daughter syndrome (funny how they never thought it was a father-daughter syndrome). They ignored the fact that Sarah's twin brother was a happy, healthy baby. The doctors put Sarah in the hospital. told us to stay away and force fed her until she was comatose and paralyzed on her right side. Only then did the

doctors decide maybe it wasn't psychological. The end result-besides an irreparable assault to Sarah's brain-was an emotional cauldron of guilt, betrayal, bitterness and hatred that Pam and I must dance around.

### **Constant stress**

Romance and sex were something I saw only on soap operas. Pam and I had no time to be alone. In 18 years, we had only one vacation as a couple. A night at the movies or dinner alone continued on page 52

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### Fathers' Voices

continued from page 50

was a major event. Babysitters were hard to find and Sarah's grandparents couldn't handle her any better than the babysitters.

The stress was constant. When Sarah was healthy, she was in constant search of food. We had to watch her like hawks or she would sneak food and end up sick. When Sarah was sick, it required constant vigilance to make her healthy again. In her early years, she was a guinea pig for researchers. At the time of her diagnosis, she was only the fifth known case of OTC deficiency in the country, and the other four were dead. Needless to say there was no romance, no sanctuary for retreat, no quiet from the storm.

Our social life was limited. Even friendships were defined by Sarah. The people who could not deal with her soon disappeared from our lives.

### Back at school

"Daddy! Daddy!"

I look up to see Sarah running

toward me, both arms straight out in front of her, trying to hug me from a block away. She is running, laughing, giggling and screaming with delight, all at the same time. She keeps her arms outstretched the whole way across the court-yard. I climb out of the car and try to keep from crying so she won't ask me, "Daddy, are you sad?"

She reaches me with a big hug. I pick her up and swing her around in the air, then set her down and give her a kiss. She puts her hands on the lides of my face, pulls me down and whispers in my ear, "It's not easy being the best, is it Dad?" That's her favorite question, and a routine with us.

"No, Sarah, it's not," I say.

"You're my friend, aren't you, Dad?"

"Yes, I'm your best friend."

"I love you, Daddy."

"I love you, too, Sarah."



Sarah, 24, shares a moment with David, her dad and "best friend."

And we get in the car and head for home. **EP** 

David L. Parsons graduated from Yale University with a BA in English in 1968 and an MFES in environmental studies in 1971. He lives in Barrington, Illinois with his wife, Pamela, and children, Sarah and Michael, 26, Melissa, 22, and Sean, 13. Active in the real estate profession for 22 years, he is president of a land development company and a construction company.

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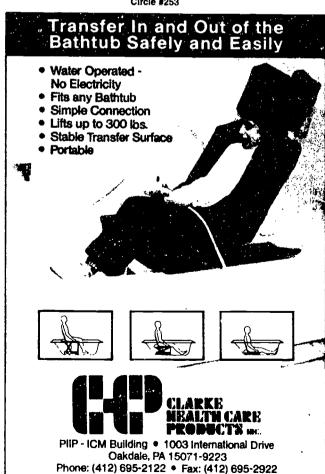


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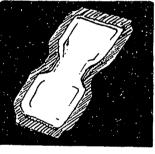


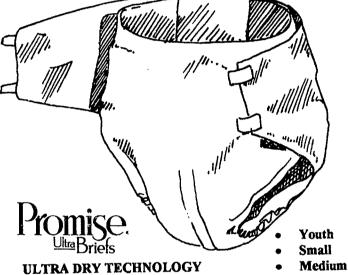
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# RECREATION

# UNIFIED SPORTS Gains Momentum At '95 World Games

by Michael Janes

he 1995 Special Olympics World Games will leave a legacy that stretches far beyond the usual remnants left behind at most athletic competitions.

That legacy will be comprised of the record number of individuals with mental retardation competing, the millions of spectators who witness the event on television and in person, and the number of sports and competitions being featured. Perhaps most significantly, these games will showcase the abundance of sports and recreation opportunities now available for individuals with mental retardation.

One of the most notable of these new opportunities is Special Olympics Unified Sports, a program that combines, on the same teams, athletes with and without mental retardation.

### Why Unified Sports?

The aim of Special Olympics Unified Sports is to provide Special Olympics athletes the opportunity for meaningful training and competition with teammates who do not have disabilities. The careful selection of teammates who are similar in age and ability ensures that Unified Sports participants play important and valued roles on the team. The program provides a forum for positive

social interaction among teammates that often leads to long-lasting friendships.

"What 'Games of Inclusion' really means is that more Special Olympics athletes than ever before are being accepted as individuals in every aspect of our program," said Dr. Tom Songster, director of sports and recreation at Special Olympics International (SOI). "The exciting part is watching them take their Unified Sports experiences into other areas of their lives, such as school, work

and their communities. Sports is simply the vehicle."



First introduced at the 1991 International Special Olympics Summer Games in Minneapolis, Special Olympics Unified Sports began with just three sports and 100 athletes. Only four years later, 11 sports—including, for the first time, golf, sailing, basketball, tennis and the marathon—will feature Unified competition. More than 1,000 Unified athletes and partners will compete together, and the numbers

continue to grow.

Unified Sports has been especially successful in schools, where teachers and administrators have struggled for years to find a way to bridge the gap between students without disabilities and their special education peers. George Smith, director of sports training

and education at SOI, says Unified Sports is one answer, noting that the program "provides an opportunity for people to have a common ground, and what better common ground than sports?" According to Smith, virtually any sport can be successfully incorporated into a Unified program, including those traditionally thought of as "individual" sports.

In his 10 years at SOI, Smith, whose responsibilities include the worldwide implementation of Unified Sports, has seen the program expand into nearly 30 countries. "You can take any sport and it can be logically, thoughtfully and successfully unified," says Smith. "It's remarkable to see the Unified concept catch on so quickly overseas, since the whole idea of inclusion is a relatively new one in some regions outside the United States."

### Goals

The goals of Special Olympics Unified Sports are:

• Skill development: Under the direction of qualified coaches, participants develop sports skills as well as prepare





themselves for participation in other community sports programs.

- Competition experiences: Athletes benefit from physical and mental challenges through participation in a variety of competitions organized by Special Olympics or by community sports organizations.
- Meaningful inclusion: Unified Sports rules and guidelines on age and ability grouping help ensure that all athletes play an important, meaningful and valued role on the team.
- Community-based participation: Unified Sports programs have found valuable partners in community parks and recreation departments, schools, Boys and Girls Clubs of America and many other community sports organizations. These partnerships help further include athletes in their community.
- Friendship and socialization: The program provides a forum for positive social interaction between teammates and often leads to long-lasting friendships.
- Transition and choice: Unified Sports programs help schools meet the transition mandates of the Individuals with Disabilities Education Act (IDEA) as well as providing a choice for athletes in and out of Special Olympics. "If you're a high school kid whose abilities aren't quite good enough for the Junior Varsity or Varsity teams yet, a Unified league provides the perfect forum for honing those skills," says Smith. "This program is all about choice, both for Special Olympics athletes and non-Special Olympics athletes."

### **Recruiting Players**

The recruitment of players is one of the most important aspects of Unified Sports. When promoting Unified Sports to potential participants, the goal is to recruit approximately equal numbers of athletes with and without mental retardation, of similar ages and with similar athletic abilities.

Like any Special Olympics competition, athletes must fit the following criteria for participation in Unified Sports: age eight years or older and having mental retardation (or learning or vocational difficulties due to cognitive delay). Because Special Olympics ath-

# Take Me Out to the Ballgame

y 24-year-old son, Matthew, has been playing in a softball league for nine years. Matthew, who has Down syndrome, does not hit the ball hard nor does he catch well, but he is good on ground balls, makes short throws accurately—if a little slowly—and delivers more strikes than balls when called upon to pitch. He understands the game and loves to play.

Special Olympics made it possible for Matthew to succeed at this complicated game. More specifically, Unified Sports enabled him to play with peers who do

not have disabilities (known as "partners") in a traditional softball league format where each team has an equal number of Special Olympians and partners.

Matthew began playing unified coftball in 1987 in Fairfax County, Virginia. It was rewarding to see people with disabilities and of varying proficiencies play in a bigtime sport, complete with umpires, cheering spectators, score books, league standings and a final tournament that included individual trophies and a picnic.

rour teams make up the top-level division where some Special Olympians can play almost as well as their partners. Although Matthew is among the weaker players and could just as easily fit in the next lower division, he plays on one of these teams.

The second division consists of six teams. At this level, partners contribute more to the games to keep play flowing smoothly. They spend more time teaching and must moderate their own play to complement the Special Olympians.

The third division consists of four teams of athletes who need more assistance. Often extra strikes are allowed to enable a batter to become a base runner. Sometimes, a partner drops a ball so a runner can safely reach first base.

The fourth level has only two teams. Unlike the other divisions where partners—and occasionally Special Olympians—pitch, balls are hit from a tee.

Two years ago, Matthew moved into a local group home with three other young men and a counselor. His job, Special Olympic sports, social and religious activities, and his family are his main interests. In addition to softball, he swims, bowls and plays basketball and soccer.

Special Olympic sports, particularly softball, have contributed much to Matthew's well-being. Our softball players range in age from their teens to their 60s and it comforts his mother and me to believe it will be around for a long time. Who knows, Matthew may have a 60-year career. He might even become a power hitter someday.

—Cecil G. Goad Vienna, Virginia

letes are matched with teanmates of similar abilities, the most appropriate Special Olympics athletes will usually have a relatively high level of athletic ability. Those who do not yet possess the requisite skill level will find more meaningful training and competition opportunities on a regular Special Olympics team.

Unified Sports "partners," or players without disabilities, generally describe themselves as "recreational level" or "beginner players." The program is not designed for individuals who are participating on a varsity or junior varsity team at the high school or college level, or those who have competed at that level in the recent past. Such players are encouraged to participate in Unified

J. B. G

Sports as coaches and trainers.

County, Virginia unified softball team.

Unified Sports has received ongoing support from sports organizations such as the Amateur Softball Association, Billiard and Bowling Institute of America, National Recreation and Parks Association, Soccer Industry Council of America and the United States Olympic Committee.

For more information on Special Olympics Unified Sports, contact Special Olympics International, Director of Unified Sports, 1325 G St. NW, Ste. 500, Washington, DC 20005, (202) 628-3630.

Michael Janes is the media relations coordinator of Special Olympics International.



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Special Olympics participation is open to individuals who are over five years of age, and who have mental retardation or cognitive delays. Children may begin participating in Special Olympics competitive events at the age of eight. For more information on Special Olympics, contact Special Olympics international Headquarters, 1325 G St., NW, Ste. 500, Washington, DC 20005-4709, (202) 628-3630 (volce).

This spring and summer, Special Olympics state games will be conducted by ali 50 state chapters. Prior to state games, athletes will compete in local or area competitions that will take place in more than 1,500 sites around the country. Athletes

will compete in such sports as swimming, softball, running, equestrian events and bowling. For more information on Special Olympics events in your area, contact your state's chanter (Phone numbers listed are for volce only)

bowling. For more information on special digitalities events in your area, contact your state's chapter. (Phone numbers listed are for voice only.)

More than 450,000 athletes will take part in Special Olympics competitions this year; some will have the opportunity to represent Team USA at the 1995 Special Olympics World Summer Game3 in New Haven, Connecticut, July 1–9. For more information on the World Summer Games, contact 1995 Special Olympics World Summer Games, 195 Church St., 16th Fl., New Haven, CT 06510; (203) 498-7773, (203) 498-9618 (fax).



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This is hydrotherapy at Berkshire Meadows.

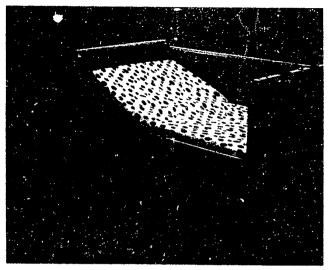
For the boy in our picture above, the intense relaxation of the Hubbard Tank helps to maintain his range of movement. Kept at a water-temperature of 98 to 102 degrees, the butterfly-shaped tank has a seat that can be adjusted to a myriad different angles to accommodate whatever physical disabilities he has. The water is pumped through jets that can focus on any one area of the body, or provide constant high-speed circulation. Not only does this therapy maintain and improve his flexibility; it gives him relief from muscle spasms and pain, and provides sensory stimulation that increases awareness of his body parts. After half-an-hour's hydrotherapy he returns to his classroom calmer, more co-ordinated and more focused. His limbs are more relaxed and have better range of motion than at any other time.

The young woman in the therapeutic pool also enjoys a variety of benefits from hydrotherapy. The water is kept at around 94 degrees, and the air temperature in the room just about the same. The pool has a moveable floor, allowing greater flexibility in programming and easy entry and exit. The reduction of gravity's effect enables the youngsters, when in the pool, to move in ways in which otherwise they cannot: when in the water they might walk independently, or might acquire real movement instead of spasticity. Here, in the supportive, liquid warmth, weak muscles are strengthened, blood circulation improved, paralyzed muscles re-educated. Balance, co-ordination and posture are enhanced, and socialization, independence, and self-esteem fostered.

Hydrotherapy is just one part of a multifaceted program at Berkshire Mead ows, a private, non-profit residential school for children and adolescents who are severely developmentally delayed and may be multiply disabled. Our program includes thorough medical, psychiatric and nursing care, speech therapy and augmentative communication, behavior management, physical therapy and functional communication. An innovative approach to education includes sensory stimulation, self care, and the development of precognitive, cognitive, pre-vocational and independent living skills. We have an open-door visiting policy, with each client's family encouraged to participate in all aspects of their child's program.

For further information, please contact: Gail Charpentier, Executive Director, Berkshire Meadows, 249 North Plain Road, Housatonic, MA 01236 (413) 528-2523

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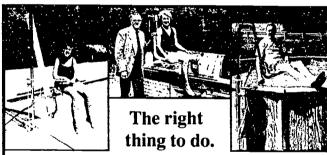
The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.



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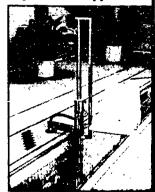




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# RECREATION

hen I watch the Boston Marathon every April, I am moved beyond words as the first racers cross the finish line in their wheelchairs. I am still overcome as the final chair rolls in many hours later. The runners, of course, are first-rate athletes, but Jean Driscoll, record-setter and four-time Boston winner in the wheelchair division, is my true hero.

This year was the first time that my daughter watched the race from her wheelchair. So my interest was even greater, my emotions more easily ignited. Kinsey is quadriplegic and at age four, she is not yet thinking about training for a marathon. But whatever the future holds for Kinsey, it is my fervent hope that she will have access to and enjoy a variety of sports. Equally important, I hope she will reach a reasonable level of fitness. But even at age four, she has already come up against many barriers—physical psychological and social-that no physician, teacher or therapist has sufficiently addressed.

Sports and fitness are not always about competition. In fact, the great majority of people, both with and without disabilities, do not race in marathons or compete in championships; they simply want to get a decent workout on a regular basis and have some fun.

Are children and young adults with disabilities getting adequate opportunities for fitness? Or will they lead sedentary lives, with a greater incidence of weight problems, hypertension, high cholesterol and heart disease? If we don't address physical fitness with our children, specifically cardiovascular fitness, such problems may be inevitable.

### Fitness versus recreation

For children with physical disabilities, opportunities for sports and recreation are better and more abundant than ever. A growing number of ski areas have programs for children with special needs and offer sitski and monoski instruction. Equestrian programs for riders with disabilities are available in many states. And national organizations and community-

based programs for wheelchair sports—everything from tennis to rugby-are on the increase. These efforts should be applauded, not to mention used and enjoyed to the hilt. However, not every sport provides the cardiovascular workout necessary for long-term health benefits.

Fitness is a major concern for many clinicians, including Karen Pape, M.D., a neonatalogist and neuropsychologist at the McGee Clinic in Toronto, Canada. She believes health care professionals need to address the topic with their patients with disabilities-as they do with all other patients. "If you diagnose a child with diabetes and simply prescribe insulin,

# **Focus** on Fitness

by Naomi Angoff Chedd

you would be remiss, even liable. You need to provide complete nutritional, exercise and lifestyle guidelines," she says.

"We should be training children with disabilities like longdistance runners, not sprinters. That is, they need high repetition of cardiovascular exercises and not necessarily a lot of weight training. Think about how world-class athletes train, then adapt the program for kids with disabilities."

"The more severe the physical disability, the more you need to look to the water for the

Naomi Chedd and daughter Kinsey, 4, participate in a weekly swim program sponsored by Massachusetts Easter Seal Society.

solution," advises Dr. Pape. Swimming and water exercise get the heart pumping; increase coordination, endurance and range of motion (of limbs) and can often reduce spasticity. Most important, it's fun. With regular exercise, grades, attitude and appearance may improve, and attention span can increase. Dr. Pape adds, "No matter what the disability, you can increase the level of fitness."

Dick Crisafulli, director of recreation at the

Massachusetts Hospital School in Canton, Massachusetts, believes that the greatest challenges come in adapting programs because each child and each disability are so different. He also says that skill development often takes a lot longer for kids with disabilities. What an able-bodied child can learn in a few classes may take a child with a disability 20 classes. "You need to have time, patience and commitment, but success does come," Crisafulli says. "Take the kids to a ballgame, to the ballet, to tournaments. Get them to ask to participate. You need to work with them on a psychologi-

continued on page 64



# DISABLED CHILDREN'S RELIEF FUND

# **Grant Programs**

DCRF grant applications are available for assistive devices, rehabilitative services, and arts and humanities projects for disabled children, up to the age of 18 years old. Applications may be submitted for an individual child or a small group of children. There are three (3) grant programs:

ASSISTIVE DEVICES: Individual disabled children are eligible for assistive device grants. This program is designed to provide disabled children with prostheses, assistive devices, and equipment such as wheel chairs, electronic light amplifiers for the vision impaired, telephone devices for the deaf (TDDs), walkers, and stair climber aids. This list is not allencompassing of fundable devices; it is provided for illustration purposes only.

**REHABILITATIVE SERVICES: Individual** disabled children are eligible for rehabilitative service grants. This program is designed to provide rehabilitation services for disabled children, including but not limited to, surgery, physical therapy, and related health improvenent services. This list is not all-encompassing of fundable rehabilitative services; it is provided for illustration purposes only.

INSTITUTIONAL GRANTS: Hospitals, rehabilitation centers, and nonprofit organizations that serve disabled children are eligible for institutional grants. Institutional applicants may request funds for assistive devices, rehabilitation services, or arts and humanities projects for two or more children (Institutions interested in a grant for only one (1) child should use the assistive devices or rehabilitative services grant applications). Applicants requesting funds for arts and humanities projects are encouraged to design creative programs. There are no restrictions on the program activities of this component, except that the activities must focus on encouraging and assisting disabled children in the arts and humanities. This program is designed to stimulate creative efforts, with preference for projects developed by children with disabilities.

For an application or more information call or write: DISABLED CHILDREN'S RELIEF FUND 50 HARRISON AVENUE, FREPORT, NEW YORK 11520 (TELEPHONE NUMBER 516-377-1605)

Focus on Fitness

continued from page 63

cal and physical level. They need to think, 'I bet I can learn to play tennis."

Another physical education instructor comments, "Kids with disabilities need to tell their coaches, 'Hey, I don't want to be the scorekeeper; I want to play.' Somebody needs to help them-and the rest of us-develop the right attitude."

More training and support needed

Paul Gorman of the National Center for Sports for the Disabled in Boston hopes his new organization, still in development, will serve as a regional model and resource that will provide fitness opportunities for people with disabilities, and training and support for professionals. The center will work with health care providers, teachers, therapists and parents to ensure that people with disabilities get equal access to sports and fitness programs.

Gorman wants to show the community how programs can be integrated and how they can work. He points out that many schools are trying hard to include kids with disabilities in their physical education programs but they need more education and support.



Photo courtesy Massachusetts Hospital School, Canton, MA.

### What can parents do?

I can hear the moans and groans from coast to coast: "I'm a mother, not an athletic director..." "My daughter already gets physical therapy twice a week ... " "With all the medical and therapy appointments, don't I have enough to do?"

The reality is that parents have to take charge of their children's fitness. The good news is that there are many committed professionals who are willing to help. Here are a few suggestions:

- Enlist the nelp of your pediatrician. Many physicians don't even bring up the subject of fitness. They may never think of it, or knowing that parents of children with disabilities are already overworked and overtired, may believe they would not be interested. Let your child's doctor know that fitness is a priority. Ask for nutritional guidelines, too.
- Devise a plan with your PT and OT. They are the ones who know your child's physical capabilities best and can identify ways for the child to work toward an optimum level of fitness.

521

continued on page 66





You can see the delight in Rebecca's eyes. When she answers a math question in her fifth-grade class-room...or creates art to hang in the halls of her school..or sings with the choir in a program at City Hall..she enjoys discovering her world.

Rebecca was eight when she arrived at Heartspring. She was unable to express herself... uncontrollable in her home...and uncooperative with her teachers. She was making no progress in a regular classroom, but her parents were reluctant to see their daughter assigned to one-to-one programming. Today, thanks to a program designed to meet this special child's needs,

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At Heartspring, a caring team of specialists take the time to discover each child. Together with the parents, they develop an individual education plan (IEP) to fit the child's needs.

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continued from page 64

- Work closely with your child's physical education (PE) instructor. And get your PT and OT involved, too. It might not take much to give your child more opportunities for fitness—a few strategies for including your child in an activity or ideas for adapting a piece of equipment. Most PE teachers do not have the time or training to individualize programs for every child with special needs, but as one instructor told me, "I'll try anything you suggest."
- Identify community programs and classes. Swimming, self-defense, yoga, aerobics and gymnastics classes are often available at "Ys" and fitness centers. Many have not included children with disabilities only because they've never been asked. Others may need help in tailoring the class to your child's

needs. Your PT and OT can advise you on appropriate activities and the equipment and support your child might need for a specific activity.

• Get wet! If at all possible, get your child into the water and



moving as often as you can. Approach your local "Y" or community pool about starting a program for swimmers with disabilities. A number of available devices can make rigorous aquatic exercise possible. An aquajogger, which is a vest that keeps a person buoyant and vertical, can allow a child to "jog" in the water

• Be a good role model. If exercise is a regular part of your routine, your kids will want to join in. Try to participate in an activity you really enjoy; enthusiasm and motivation are contagious. Summer is a good time to begin a cardiovascular fitness program. When school begins in the fall, the school PE instructor can work with your child to maintain a higher level of fitness, rather than starting from scratch. And remember—you can

write physical education goals into your child's IEP.

Naomi Angoff Chedd is a member of Exceptional Parent's editorial staff.

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Circle #

# RECREATION

# Role Models

# **Mary Verdi-Fletcher**

Born with the spirit of a dancer

Mary Verdi-Fletcher, 39, is principal dancer and founder of the Cleveland Ballet's Dancing Wheels, a company established in 1980 for people with disabilities to explore the world of dance. A second Dancing Wheels company, called Danceability, has been established in Atlanta; a third is being developed with Ben Vereen's performing arts school in Chicago. Verdi-Fletcher is also president of Professional Flair, a nonprofit arts/disability organization. The Cleveland native and Lakeland Community College graduate has spina bifida. She lives with her husband, Bob, in a Cleveland suburb. The following was adapted from a recent interview between Verdi-Fletcher and Michele San Filippo, an EXCEPTIONAL PARENT intern.

onneone once said to me that the arts are a vocation that chooses you; you don't choose them. I believe I was born with the spirit of a dancer and it was through fate I was able to pursue it.

I started dancing at the age of three. I would groove to the radio all the time. I remember doing the Mexican hat dance at age five when the nuns of Our Lady of Lourdes Shrine in

Cleveland asked me to dance. Once a month, I would break my braces while dancing; then I broke my leg three times because I got new braces that were too strong. I even broke my wheelchair a few times.

In 1975, I became involved in dance on a social level and began going out dancing in groups. I liked popular dances, mostly freestyle and disco, but also enjoyed ballroom.

My mother, a professional dancer for 15 years, inspired me to dance. My dad, a General Electric quality-

control technician, played saxophone and clarinet parttime until about 12 years ago. Hearing my parents' stories



Five-year-old Mary (left) enjoys her first "dance lesson" with her mom Nancy, cousin Rita and brother Brian.

of their vaudeville days during the war, really made me interested in dance. My parents met on the stage while Mom danced and Dad played "Moonlight Serenade" in the orchestra pit. I also enjoyed watching movies with Gene Kelly, or Fred Astaire and Ginger Rogers.

### Sheltered childhood

When I was born, little was known about spina bifida, and there were no parent groups. My parents were told I wouldn't live past the age of three and if I did live that long, I would be a "vegetable." The doctors encouraged them to put me in a home. Luckily, they didn't.

In 1950, babies with spina bifida were sometimes just left to die; I was born in 1955, after doctors started keeping babies alive and trying to find ways to help them. The doctors didn't know what to expect. I had one of the worst cases of spina bifida they had ever seen.

My parents were afraid to let me be independent. They were very protective and didn't allow me to go out with friends. They did it out of love and fear, but their protectiveness prevented me from developing social skills like other youngsters. My parents were big proponents of education, however, and wanted to give me the best schooling possible.

My mom took me to Villa Angela Academy, a Catholic, all-girls high school, every day. She would stay to carry me upstairs so I could attend class with able-bodied kids. She ended up getting an audio-visual job at the school just to be around for me

For two years I attended this inaccessible 90-year-old school with many stairs and a rickety elevator. In my sophomore year, a new one-level building was built; I could get around a *lot* better. I really had a good time there studying voice and performing in all the theater produc-

continued on page 70



Young Mary meets Pope Paul VI in 1965 with her grandmother, Marghrita Baruzzi (far left), and mother Nancy.

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continued from page 68

tions. A few years ago, I was chosen by the Sisters to be in the Villa Angela Academy Hall of Fame.

### Love and respect

My relationship with my parents was like a wave. There were times when I loved them dearly; but other times, I felt resentful. I was resentful for a while because I wasn't allowed to go out and be with other kids. I resented that they didn't think I would ever be married because of my disability. But, I got over it and understood why they felt the way they did. No matter what, I have always had love and respect for them.

My parents dealt with my disability the best way they knew how. I grew up with my older brother and cousins, which was very positive because my parents wanted me to be seen as their equal. Some of what my parents did



was very helpful, because I grew up among able-bodied peers.

My parents always prayed for a miracle because that's what you did back then. I think the fact that I am here today is a miracle, given my 10 major surgeries growing up and three recent ones due to kidney problems.

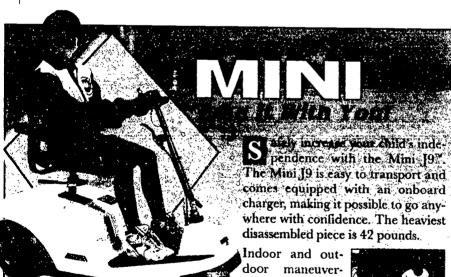
### **Becoming independent**

When I was in my mid-twenties I decided to pursue the things I wanted in life. A friend told me, "You have to learn not to take 'no' for an answer" and "For every door that closes, another one opens."

I didn't have many boyfriends back then because of my parents' protectiveness. If your mom is pushing you in

continued on page 72

Nancy Verdi (left) inspired daughter Mary to dance. This 1937 photo shows Nancy and twin sister Rena during their vaudeville days.

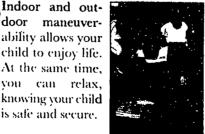


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Olaula 40

# Best Wishes! to all the Athletes

from your friends at EXCEPTIONAL PARENT



# Superior Quality Community Living Opportunities

For more than 65 years, Martha Lloyd Community Services has provided superior quality day, residential and vocational programs for adults with mental retardation. Located in the scenic rural village of Troy, Pennsylvania, Martha Lloyd has a unique relationship with its neighbors. Residents are valued members of the community and make full use of its resources. Few other programs can offer such an open and productive relationship.

There are five programs for women (from semi-independent to supportive) including one specifically designed for mature women. A new community-based program for men has been added. The program offers training in home care and maintenance, budgeting, household management, and participation in an established vocational program.

### **All Programs Offer These Advantages**

- Life skills and vocational training.
- Employment opportunities at Martha Lloyd and in the Troy community.
- Easy access to nearby community resources including retail shops, restaurants, churches, and recreation.
- A caring professional staff experienced in working with developmental disabilities.

- Our interdisciplinary team approach assures continuity and consistency in individual planning.
- Unique leisure and recreational experiences in a rural community setting.
- Excellent health care provided by on-staff health professionals and a community medical center.
- Annual fees among the lowest in the nation.

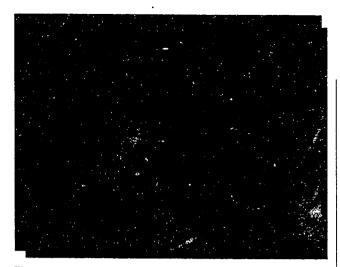


MARTHA LLOYD COMMUNITY SERVICES

For Information Call **(717) 297-2185** 

or write: Martha Lloyd Community Services 190 West Main St., Troy, PA 16947





The Dancing Wheels company includes performers with and without disabilities. (From left) Barbara Allegra Verlezza, Mark Tomasic, Sabatino Verlezza and Mary Verdi-Fletcher.

continued from page 70

your wheelchair, you won't have many guys coming up to you. Once I decided to become independent, I learned to drive a car and got a job. Within two years, I had tripled my salary and found someone at work I could room with. It was a major shock to my parents because they always expected me to live at home.

When I first told my parents I was moving out, they

### Role Models

told me never to come home again. They hoped that would somehow keep me there. My response: "I need to leave, and I hope you will support me if I don't do well because I'm not sure how I will manage."

At that point I asked myself, "When I am 40 or 50, am I going to look back on my life and say, 'I should have done this or that?" I'd much rather take the risk and hope things work out for the best.

### Realizing the dream

Once I started to pursue a career in dance, it just happened. I knew I loved dancing and my dancing gave both able-bodied people and people with disabilities a different view of disabilities. Dance was still an art form that had not yet been explored by the disability community.

In 1980, I began getting paid as a Dancing Wheels performer. I danced part-time for many years while working full-time as development director of a non-profit organization serving people with disabilities.

In 1989, I decided to pursue dance full-time. I didn't know any professional dancers who had a disability, but I figured why not?

At first, people didn't believe I was a dancer, but when they saw me dance, they believed. Then, they questioned

continued on page 74



# Keep Your Child Buckled In With SeatKeeper™



Make
Every
Ride A
Safer Ride
For Your
Active
Child

Installs on seat belt to assist in keeping children or special needs people buckled up.

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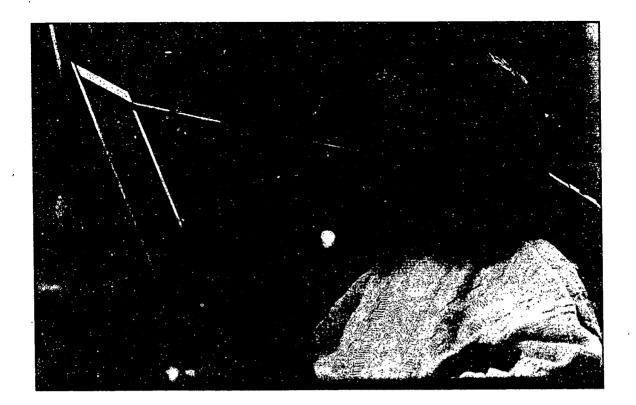
512-406-9551 or 1-800-SeatKeeper

A Product of Child Quest, Inc.
Austin, Texas

EXCEPTIONAL PARENT / JUNE 1995







# The Joy of Independence

The joy of self-expression shines every day for students at Crotched Mountain Rehabilitation Center. Just 50 miles from Boston, surrounded by New England villages and towns, freedom and independence are celebrated with every graduating class. Throughout our progressive 60-year

tradition, students have been realizing their dreams and achieving success.

Here, families and their special children find the highest standard of care, education, and treatment. Warm, home-like residences welcome students into a supporting core, from which



Spring Time by Amy Neubauer

they explore an exciting world of creativity, expression, and accomplishment, achieved with the help of our dedicated educators and healthcare professionals.

Within our state-of-the-art facilities, children master skills of independent living. Our students exercise in the

swimming and therapy pools, pursue knowledge using multi-media computers to access the Internet, and develop self-esteem through occupational and vocational training. Students flourish here in the brilliance of success and the joy of independence.

To find out more about the compassionate and caring services we provide for special children throughout the world, please call Debra Flanders in Admissions at 603-547-3311, ext. 235.

# CROTCHED MOUNTAIN

A subsidiary of the Crotched Mountain Foundation

1 Verney Drive, Greenfield, New Hampshire 03047 internet: info(a cmf.org fax 603-547-3253 0







### Role Models

continued from page 72

whether Dancing Wheels was just "dance therapy" because some of us had disabilities.

Eventually the public started to accept us. The more they saw, the more they wanted to see and the more dances they saw, the bigger the productions they wanted to see. People now stop me on the street and say, "You're the dancer, aren't you?"

Many people think of dance in terms of only using our legs, when dance is actually an expression. It's an expression that conveus emotion. Dance comes from within, meaning it can be done in many different ways. This is the approach of dance today, but years ago it wasn't. If you couldn't use your legs, you couldn't be a dancer.

We use very high-tech lightweight wheelchairs, the Action

> Verdi-Fletcher is collaborating with Ben Vereen to expand Dancing Wheels.

line from Invacare. I use three different chairs, each of which responds very differently. My first chair was 55 pounds; these new chairs are under 20. With the flick of a finger, I can make the chair go in a complete circle and glide across the floor.

My mission is twofold. First, Dancing Wheels opens the eyes of able-bodied children to see the possibilities

> and similarities-rather than the differences—in all of us. And, second, the dance itself inspires children and adults with disabilities to feel a change within themselves. It creates self-esteem, dignity and an inner beauty that often does not come out. I see a transition in people as they take dancing classes. I see a change in the way they move and the way they feel about themselves; they exude confidence they didn't have before. I've seen it change people time and time again. EP



Haverich Ortho-Sport, Inc. 67 Emerald Street Keene, NH 03431 (603) 358-0438

Europe's leading line of specialized bicycles, tricycles and tandems now available in North America. Steel frame. Duel caliper, drum and coaster brakes available. Parking brakes standard. Latest styling and wide choice of colour combinations. More than 30 specially designed accessories to meet every need.



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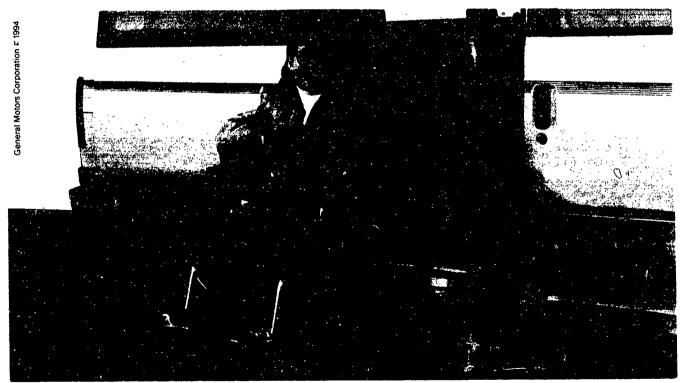
Circle #229

### **General Motors.**



"The GM Mobility Program can help you a lot.

I know because my mom is part of it."



An active honor roll student, Tammie Groth doesn't believe in obstacles. Neither does her mother, Connie, one of the many General Motors employees whose own lives are affected by physical disability. It's their valuable insights that help make the GM Mobility Program work. Transportation means independence. That's something the people at General Motors know from their own experience.

Call the GM Mobility Assistance Center. We'll give you: • The names of local companies that provide driver assessment services, adaptive driving devices and vehicle modifications. • An informative videotape, "On the Move Again." • Suggestions for the General Motors cars and trucks that might work best for you. Then, if you buy or lease a new GM vehicle, we'll reimburse you up to \$1000 toward the cost of adapting it or reinstalling your own adaptive equipment. Call 1-800-323-9935 (TDD users: 1-800-TDD-9935), or contact your Chevrolet, Pontiac. Oldsmobile, Buick, Cadillac or GMC fruck dealer to find out more.

ERI

# RECREATION

# **Recreation Resources**

This directory includes national groups and organizations that can serve as resources for recreational and sports activities for children and young adults with disabilities. Groups listed in the "General" category can provide information and referrals for a number of different recreational activities and sports.

A description of services provided by individual groups follows each listing. Numbers correspond to items listed in the Key to Services. If a group serves a specific age range and/or disability, the age range and disabilities are given in parentheses at the end of its listing. If not otherwise indicated, the group serves people of all ages and/or with all disabilities.

This symbol ( [ ) indicates an internet e-mail address. Unless otherwise indicated, telephone numbers are for voice only.

### KEY TO SERVICES

- 1. ORGANIZES NATIONAL COMPETITIONS
- 2. ORGANIZES LOCAL COMPETITIONS
- 3. TRAINS LEADERS, SUCH AS COACHES AND PARENTS
- 4. PROVIDES INFORMATION (I.E., VIDEOS, PUBLICATIONS)
- 5. GFA TRS FREE LOANER EQUIPMENT TO PARTICIPATE IN PROGRAM (I.E., RACING WHEELCHAIRS)
- 6. OFFERS EQUIPMENT USE FOR A FEE
- 7. PROVIDES FINANCIAL AID

### GENERAL

### American Athletic Association of the Deaf

3607 Washington Blvd, Ste 4 Ogden, UT 84403-1737 (801) 393-8710 (voice) (801) 393-7916 (TTY) (801) 393-2263 (fax) 1,2,3,4,5,7 (deaf, hearing impairments)

### **Boy Scouts of America**

Scouting for the Handicapped Service 1325 W Walnut Hill Ln Irving, TX 7503B (214) 580-2000 (214) 580-2502 (fax) 1,2,3,4,5



Photo by Mary Carol Peterson, Sports W Spokes/Paralyzed Veterans of America, Phoenix, AZ.

### Canadian Wheelchair Sports Association

1600 James Naismith Dr Gloucester, ON CAN K1B 5N4 (613) 748-5685 (613) 748-5722 (fax) 1 (6-60 years; wheelchair users)

### **Disabled Sports USA**

451 Hungerford Dr, Ste 100 Rockville, MD 20850 (301) 217-0960 (301) 217-0968 (fax) 1,2,3,4,5,6 (mobility impairments, visual impairments)

### Girl Scouts of the USA

Services for Girls with Disabilities 420 5th Ave New York, NY 10018 (212) 852-8000 (212) 852-6515 (fax) Different services offered through local chapters (5–17 years)

### National Sports Center for the Disabled

PO Box 36 Winter Park, CO 804B2 (970) 726-5514 (970) 892-5823 (fax) 1,2,3,4,6,7

### Perfect Fit (4-H programs)

Purdue University; Cooperative Extension Service 1161 Agricultural Administration Bldg W Lafayette, IN 47907-1161 (317) 494-8423 (317) 496-1152 (fax) 3,4 (10-19 years)

### Wheelchair Sports, USA/National Wheelchair Athletic Association

3595 E Fountain Blvd, Ste L1
Colorado Springs, CO 80910
(719) 574-1150
(719) 574-9840 (fax)

☑ Wheelchair@aol.com
1,2,3,4 (wheelchair users)

### **US Association of Blind Athletes**

33 N Institute St Colorado Springs, CO 80903 (719) 630-0422 (719) 630-0616 (fax) 1,2,3,4,5,6,7 (blind, visual impairments)

### US Cerebral Palsy Athletic Association

3810 W Northwest Hwy, Ste 205 Dallas, TX 75220 (214) 351-1510 (214) 352-1744 (fax) 1,2,3,4 (6 and older; cerebral palsy, traumatic head injuries, stroke survivors)



Photo courtesy United Cerebral Palsy Athletic Association, Dallas, TX.

### **AQUATICS**

### Dwarf Athletic Association of America

c/o Sarah Beth Ely
12101 S Mulino Rd
Canby, 0R 97013
(205) 743-3424

≤≤≤ Swimmer79@aol.com
1,2 (Persons of short stature—4'10" or less adult height—due to achondrodysplasia or similar medical conditions)

### US Cerebral Palsy Athletic Association

See listing under "General"

### US Wheelchair Swimming

C/o Larry Quintilani
229 Miller St
Middleboro, MA 02346
(508) 946-1964
(508) 946-4737 (fax)
Itquinn@aoi.com
1,2,3,4 (7 and older; mobility impairments)

533

### ARCHERY

Wheelchair Archery USA c/o Lynn Rourke 3595 E Fountain Blvd, Ste L Colorado Springs, CO 80910

(719) 574-1150 1,2,3,4

### BASKETBALL

### National Wheelchair Basketball Association

c/o David Kiley
Casa Colina Centers for Rehabilitation
2850 N Garey Ave
Pomona, CA 91769-6001
(606) 257-1623
(606) 258-1090 (fax)
1,2,3 (7-65 years; physical disabilities)

### National Wheelchair Basketball Association Youth Division

c/o Bob Szyman, Commissioner
St. Louis Wheelchair Athletic Association
6420 Clayton Rd
St. Louis, M0 63117
(314) 768-5325
(314) 768-5316 (fax)
1,2,4 (high school students, 21 and under, physical disabilities)

### **USA Deaf Basketball**

c/o Bennie Maucere
3964 Murietta Ave
Sherman Oaks, CA 91423
(818) 789-9573 (TTY)
(818) 789-2087 (fax)

| Jamesr111@aol.com
1,2,3; Offers youth basketball camp

### BOCCIA

### US Cerebral Palsy Athletic Association

See listing under "General"

### **BOWLING**

### American Blind Bowling Association

c/o Ron Beverly, Editor/PR 67 Bame Ave Buffalo, NY 14215 (716) 836-1472 1,2,4,6 (18-80 years; blind, visual impairments)

### US Cerebral Paisy Athletic Association

See listing under "General"

### **US Deaf Bowling Federation**

c/o Connie Marchione 8071 Cherrystone Ave Panorama City, CA 91402 (818) 785-1478 (TTY) 1,2,3 (14 and older; deaf, hearing impairments)

continued on page 78

# Our customers know... second best simply isn't good enough.

MICRO OVERFLOW CORPORATION

LUCA AND SOLD SUIT SET AND THE SE ANGEL YES

March 17, 1994

I owe my life to this restraint system, and I just wanted to thank you. Keep up the good work. Needless to say, my new van will be equipped with Qaitraints.

Donald J. Daleen

Donald J. Button. President, Micro overflow Correlation

November 8, 1993

O'Straint 3085 Southwestern Blvd. Orchard Park, New York 14127

Dear Mr. Reaume:

Your company may have very well saved my life, for that I sincerely thank you. Here is my story.

I am a disabled person working for a wheelchair transit company. I schedule the buses with passengers. On November 3, 1993, I was a passenger in a para transit bus which was involved in a 2 vehicle collision. In this collision this bus was flipped over on its side. I am a very heavy person 200 lbs +. My wheelchair was secured in the vehicle with the Q'Straint system. I did not even move in this incident. I contribute this to the driver using your system correctly and obviously it must be one terrific system. I shudder to think of the scenarios of what might have happened had they not done their job. I sustained minor injuries. My wheelchair has had to have some repairs done to the front casters which were pushed back in the accident. This prevented my chair from being used as the front casters would not rotate. I strongly believe if the driver did not use this system as it was meant to be used. I would not be able to write this note to you. You have created one great system. Many thanks.

Linda Shore France

Linda Jane France



16 - 100 Sheldon Dr. Cambridge, Ontario

Dear Mr. Gitardin.

Just a quick note to advise of a recent incident Handi-Transit was involved in, and the role Q'Straint played in it. Our bus was involved in a collision after a local utility van ram a red light causing it to collide broadside with our bus. The van was destroyed, our bus sustained damages in excess of \$15,000; the three wheelchair passengers secured with Q'Straints did not move.

HANDI - TRANSI

3737 Walker Road

Windsor, Ontario

NSW 159

Yout product, which we use exclusively, did the job it was supposed to do. Thank you for a superior product in a day when mediocrity is the norm-

Yours sincerely.

C. Douglas Ellis.



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Circle #251

### **O'Straint (USA)**

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Phone: 716-675-2222 Fax: 716-675-2270

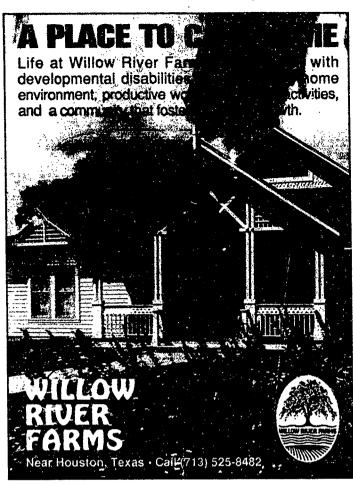
### O'Straint (Canada)

16 - 100 Sheldon Dr.

Cambridge, Ontario N1R 7S7

Phone: 519-622-0000 Fax: 519-622-0021





Circle #91

# EYSTONE

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ACCREDITED CAMP American Camping Association

200

## RECREATION



Photo courtesy Canadian Recreational Canoeing Association, Hyde Park, Ontario.

### CANDEING

American Canoe Association, Inc. **Disabled Paddlers Committee** 7432 Alban Station Blvd, B-226 Springfield, VA 22150 (703) 451-0141 (703) 451-2245 (fax)

ACA Direct@aol.com 1.2.3.4

### **Canadian Recreational Canoeing Association**

1029 Hyde Park Rd. Ste 5 Hyde Park, ON CAN NOM 1Z0 (519) 473-2109 (519) 473-6560 (fax) 3,4,5,6

### CROSS COUNTRY

US Cerebral Palsy Athletic Association See listing under "General"

### KEY TO SERVICES

- 1. ORGANIZES NATIONAL COMPETITIONS
- 2. ORGANIZES LOCAL COMPETITIONS
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- 4. PROVIDES INFORMATION (I.E., VIDEOS, PUBLICATIONS)
- 5. OFFERS FREE LOANER EQUIPMENT TO PARTICIPATE IN PROGRAM (I.E., RACING WHEELCHAIRS)
- 6. OFFERS EQUIPMENT USE FOR A FEE
- 7. PROVIDES FINANCIAL AID

continued from 76

### CYCLING

**USABA Sports Director** for Tandem Cycling c/o Bill Young 2878 Copley Ave San Diego, CA 92116 (619) 281-1621 1,2,4,5 (blind)

**US Cerebral Palsy Athletic** Association See listing under "General"

**US Deaf Cycling Association** c/o Bobby Skedsmo 2625 Copa Del Oro Dr Union City, CA 94587-3175 (510) 471-9011 (TTY/fax) 1 (unaided bilateral hearing loss of 55 dB or greater)

### **FISHING**

See Also: "Outdoor Recreation/Wilderness Exploration"

Fishing Has No Boundarles PO Box 175 Hayward, WI 54843 (800) 243-3462 (715) 634-3185 (715) 634-1305 (fax)

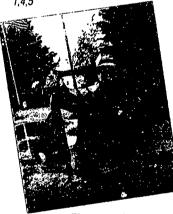


Photo courtesy Fishing Has No Bounderies, Hayward, Wi.

### GARDENING

**American Horticultural Therapy Association** 362A Christopher Ave Gaithersburg, MD 20879

(301) 948-3010 (301) 869-2397 (fax) 253 75352.122@compuserve.com

continued on page 80

# Rock N' Roll Cycles

Custom fitted fun for all ages!

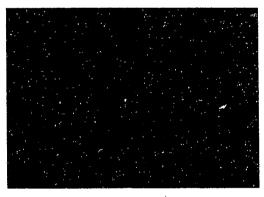
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Spina Bifida **Cerebral Palsy Partial Paralysis Amputations** Orthopedic Handicaps Visual Impairment/Blindnes Muscular Dystrophy



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- Covered by most insurance companies.

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- * S.M.L



### **AQUATIC THERAPY FLOAT**

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Circle #118

# 1Ms School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

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- Occupational Therapy
- Special Medical Attention
- · Speech and Language Therapy
- Adapted Recreational Activities

Communication Aids

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> For more information write or call: Diane L. Gallagher, Director

HMS School for Children with Cerebral Palsy 4400 Baltimore Avenue, Philadelphia, PA 19104 (215)222-2566



# RECREATION



Photo courtesy United Cerebral Palsy Athletic Associatin. Dallas, TX.

continued from 78

### GOAL BALL

**USABA Sports Director for Goal Ball** c/o Stephen Kearney, Director of Athletics . Oklahoma School for the Blind 3300 Gibson St Muskogee, OK 74403 (918) 682-6641 (days) (918) 683-0338 (evenings) (918) 682-1651 (fax)

Signature (918) 682-1651 (fax) 1,2,3,4,5,6,7 (8-45 years, visual impairments)

### HORSEBACK RIDING

North American Riding for the Handicapped Association c/o Bill Scebbi PO Box 33150 Denver, CO 80233 (800) 369-7433 (303) 452-1212 1,2,3,4

### ICE HOCKEY

American Hearing Impaired **Hockey Association** c/o Irv Tlahynbik 1143 W Lake St Chicago, IL 60607 (312) 226-5880 (312) 829-2098 (fax) 1,3,7 (10-20 years; unaided bilateral hearing loss of 55 dB or greater)



Breckenridge Outdoor **Education Center** PO Box 697 Breckenridge, CO 80424 (303) 453-6422 (303) 453-4676 (fax) 2.3.4.7

Cooperative Wilderness Handicapped Outdoor Group Box 8118, Pond Student Union Idaho State University Pocatello, ID 83209 (208) 236-3912 (208) 236-4600 (fax) 3,4,5,6,7

**Courage Center** 3915 Golden Valley Rd Golden Valley, MN 55422 (612) 520-0520 (612) 520-0577 (fax) 2,4,5 (physical disabilities)



Photo courtesy **Breckenridge Outdoor Education** Center, Brekenridge, CO.

**Environmental Traveling** Companions Fort Mason Center Landmark Bldg C San Francisco, CA 94123 (415) 474-7662 (415) 474-3919 (fax) 3,4,7 (10 and older)

continued on page 82



Photo courtesy Breckenridge Outdoor Education Center, Brekenridge, CO.



**EXCEPTIONAL PARENT / JUNE 1995** 



## RECREATION



Photo courtesy Sports 'N Spokes/Paralyzed Veterans of America, Phoenix, AZ.

### KEY TO SERVICES

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- 6. OFFERS EQUIPMENT USE FOR A FEE
- 7. PROVIDES FINANCIAL AID

continued from 80

**National Park Service** 

Office on Accessibility 800 N Capitol NW, Ste 580 Washington, DC 20002 (202) 343-3674

(202) 343-4230 (fax) Provides accessibility information for national parks

Paraplegics on Independent

**Nature Trips** c/o Carol Barrett 4144 N Central Expwy Dallas, TX 75204 (214) 827-7404

(214) 414-3772 (fax) 1,2,4,5 (physical disabilities) Wilderness Inquiry 1313 Fifth St SE, Box 84 Minneapolis, MN 55414 (800) 728-0719 (612) 379-3858 (612) 379-5972 (fax)

### **PERFORMING ARTS**

**Association for Theatre** and Disability

c/o Access Theatre 527 Garden St Santa Barbara, CA 93101

(805) 564-2063 (805) 564-2424 (TTY)

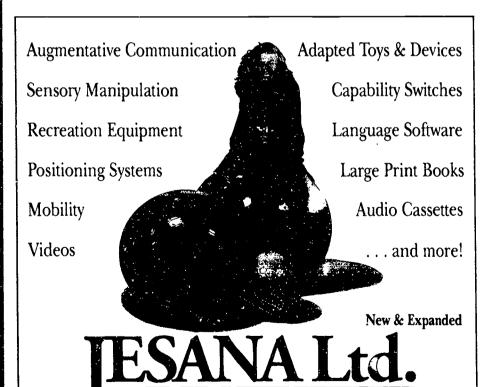
(805) 564-0051 (fax)

Rippyrod@aol.com Maintains national talent bank of artists with disabilities, organizes national conference on accessible theater every August

continued on page 84

Photo courtesy The Cooperative Wilderness Handicapped Outdoor Group, Pocatello, ID.





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# RECREATION

continued from 82

### **PowerLifting**

**US Cerebral Palsy Athletic Association** 

See listing under "General"

### **QUAD RUGBY**

Wheelchair Sports, USA See listing under "General"

### RACQUETBALL

### National Wheelchair Racquetball Association

c/o Geno Bonetti Director of Spinal Cord Programs Healthsouth Rehabilitation Hospital of Pittsburgh 2380 McGinely Rd Monroeville, PA 15146 (412) 856-2468 (412) 856-2437 (fax) 1,2,3,4,5 (wheelchair users)

# SAILING

### Access to Sailing

c/o Duncan Milne 19744 Beach Blvd, Ste 340 Huntington Beach, CA 92648 (714) 722-5371 2,3,4,5 (6 and older)

## **National Ocean Access Project**

PO Box 10246 Rockville, MD 20849 (301) 217-9842, ext 6

# **Ontario Sailing Association**

Committee for Sailing for Disabled Persons 1185 Eglington Ave E North York, ON CAN M3C 3C6 (416) 426-7271 (416) 426-7344 (fax) 1,2,3,4,5,6



Photo courtesy The Cooperative Wilderness Handicapped Outdoor Group, Pocatello, ID.

### **US Sailing Association**

Committee on Sailors with Special Needs PO Box 209 Newport, RI 02840 (401) 849-5200 (401) 849-5208 (fax)

Sailing@compuserv.com 1,3,4,6

### SCUBA

### Moray Wheels: Adaptive Scuba **Association**

PO Box 1660 General Mail Facility Boston, MA 02205 (603) 598-4292 3,4,5 (14 and older, physical disabilities)



Photo courtesy American Sledge Hockey Association, Bloomington, MN.

National Instructors
Association
for Divers with Disabilities
PO Box 112223
Campbell, CA 95011
(408) 379-6536

deshrout@aol.com
3.5.6

### SKIING

Canadian Association for Disabled Skling Box 307, Kimberley, BC CAN V1A 2Y9 (604) 427-7712 (604) 427-7715 (fax) 1.4.5.6

US Deaf Skiers Association c/o W. Edward Ingham 0400 Palatine Hill Rd Portland, 0R 97219 (503) 245-2192 (TTY) (503) 246-3757 (fax) ☐ Clingham@aol.com 1,2,3,4,7

# SLALOM (FOR WHEELCHAIRS)

US Cerebral Palsy Athletic Association See listing under "General"

### SLEDGE HOCKEY

American Sledge Hockey Association (ASHA) c/o John Schatzlein 10933 Johnson Ave S Bloomington, MN 55437 (612) 750-3973 (612) 888-5331 (fax) 1,3,4,5 (11-21 years; mobility impairments)

### SOCCER

US Cerebral Palsy Athletic Association See listing under "General"

### SOFTBALL

National Softball Association of the Deaf c/o Vance Rewolinski 6605 Krolton Dr. Austin TX 78745 1,2 National Wheelchair Softball Association

c/o Jon Speake 1616 Todd Ct Hastings, MN 55033 (612) 437-1792 1.5

### TABLE TENNIS

American Wheelchair Table Tennis Association c/o Jennifer Johnson 23 Parker St Port Chester, NY 10573 (914) 937-3932 (914) 937-3932 (press *51 for fax) 1,2,4 (4 and older)

### TEAM HANDBALL

UCPAA Team Handball Technical Officer c/o Bill Wilkie UCPA of Greater Hartford 80 Whitney St Hartford, CT 06105 (203) 236-6201 (203) 236-6205 (fax) 1.2,3.4 (12 and older; physical disabilities)



Photo courtesy Sports 'N Spokes/Paralyzed Veterans of America, Phoenix, AZ.

### **TENNIS**

International Foundation of Wheelchair Tennis
Peter Burwash International
Attn: Director-Special Programs
2203 Timberloch PI, Ste 126
The Woodlands, TX 77380
(713) 363-4707
(713) 292-7783 (fax)

PBI@infohwy.com
1.2.3.4.5

National Foundation of Wheelchair Tennis Brad Parks, Executive Director 940 Calle Amanecer, Ste B San Clemente, CA 92672 (714) 361-3663 (714) 361-6603 (fax) 1,2,4 (7 and older; physical disabilities)

# TRACK AND FIELD

US Cerebral Palsy Athletic Association See listing under "General"

Wheelchair Sports, USA See listing under "General"

# WATER SKIING

American Water Ski
Association
Committee on Water Skiing for the Disabled
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(813) 325-8259 (fax)

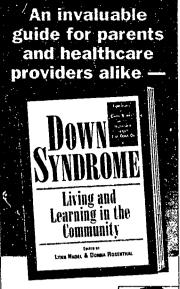
| 37024.3504@compuserve.com
1.3.4

# WEIGHTLIFTING

US Wheelchair Weightlifting Federation c/o Bill Hens 39 Michael Pl Levittown, PA 19057 (215) 945-1964 organizes international team for competition (16 and older; physical disabilities)

### WRESTLING

US Deaf Wrestling Association c/o James Schartner 4835 Mt Zion Rd Frederick, MD 21702 (301) 473-5255 1,2,3 (18-34; deaf)



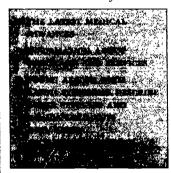
With a Forcword by Chris Burke

th by ke

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Circle #241

# RECREATION

# **Using Ordinary Toys for Kids With Special Needs:**



For more than 100 suggestions on how to easily adapt ordinary toys for kids with special needs, look at the 1995 edition of

The Best Toys, Books & Videos for Kids

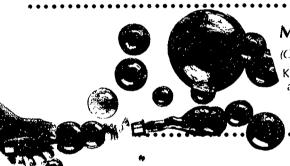
(HarperCollins, \$12) by Joanne and Stephanie Oppenheim. The book is a comprehensive guide to more than 1,000 classic and new products for children from infants to preteens. Available through Exceptional Parent Library, (800) 535-1910.

# **Outdoor Fun**

by Joanne and Stephanie Oppenheim

etting into the big outdoors is one of the delights of summer. Outdoor play is a time to let loose, to shout and laugh out loud without worrying about making too much noise or bothering neighbors. It's a time for flexing, stretching, using muscles and getting a sense of one's physical self. It's often a social time when kids learn the give-and-take of playing with others. Well-chosen toys can build children's confidence about themselves as "doers." Here are some ordinary toys for outdoor fun that may require little or no adaptations for children with disabilities.

Following each toy's name in parentheses is the name of its manufacturer, the recommended retail price and a customer service number that may be used for ordering or for more information.



# **Musical Bubble Tunes**

(CAP, \$9.99; 216/292-6363)

Kids who may not be able to blow bubbles can still have the thrill of creating a rush of bubbles with a push of a button. This bubble toy plays music when another button is pushed. It plays "Happy Birthday" and seven other tunes. Requires two AA batteries.



# **Airplane Swing**

(Little Tikes, \$25-\$28; 800/321-0183)

A parent told us how useful this airplane swing with its high back has been for her three-yearold who needs extra support for sitting. Tots practically wear this jolly airplane that holds them all around with leg holes and no place to slip through. Has an adjustable seat belt. Can accommodate children up to 50 pounds.

Activity tip: Use words like "faster" and "slower," "higher" and "lower," "stop" and "go" to reinforce these concepts in active, meaningful ways. Play pretend games in which your tot is flying to a faraway place; talk about what the child can "see" as he or she flies.





# Roll 'n Rattle Ball

(Playskool, \$9.99; 800/752-9755)

It takes very little to activate this wonderful rolling toy, but children get visual as well as sound feedback from the multi-colored, tiny beads that swirl and swish in this see-through sphere with a bright yellow and blue ball inside. The toy is not for throwing, but it's ideal for stimulating children to crawl after and swat at with whole-hand movement; use also for roll-back-and-forth social games. Needs no adaptation

Activity tip: To motivate and involve an older child, use the ball for a guessing game. Will the ball stop yellow side up or blue? Let the child guess. Then take turns spinning the ball and chant "Round and round she goes. Yellow or blue; which one mostly shows?" Of course, both colors will show, but

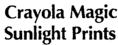


# **Double Fun Wagon**

(Today's Kids, \$33-\$45; 800/258-8697)

This innovative wagon is designed to double as a hauling or ride-in vehicle. The floor of the wagon can be closed or opened halfway to the ground so kids with disabilities can sit in it as passengers or use their legs to help it move. The handle works at child-height or telescopes for an adult to pull.

Adaptation idea: For a child who needs extra support, a seat belt with Velcro closings can be added to the high back of the wagon.

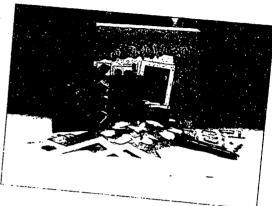


(Crayola, \$14.99; 800/272-9652)

Printing images with the sun on lightsensitive paper is like magic! This kit comes with clear directions, markers, a glitter-glue pen, acetate images, frames, stencils and 15 pieces of special print paper. Gives pleasing results

for kids who may not be able to draw with conventional art tools.

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# **Drive-In Playhouse**

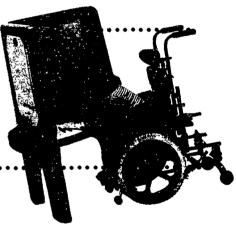
(Step Two, \$155; 800/347-8372)

A playhouse that meets today's building codes. With its double door opening (22.25 inches wide), a small wheelchair can roll right into this playhouse that has big windows, a built-in table and a cordless phone.

# **Creative Art Center**

(Step 2, \$45-\$50; 800/347-8327)

A young artist in a wheelchair can sit at the work table and paint or color. Can be used indoors or outdoors by one or several children at a time. There's room at the table for painting, chalk or crayon drawing and desktop publishing.





# Pickup Truck

(Little Tikes, \$75-\$80; 800/321-0183)

Newest in the fleet of sturdy ride-in vehicles, this foot-to-floor (no pedals) truck can build upperand lower-body coordination and imagination. Doors open for easy in and out and there's room for cargo. Includes a working tailgate.

**Adaptation idea:** For a child who needs extra support, a seat belt with Velcro closings can be added to the high-backed seat.

**Shopping tip:** Battery-operated ride-in cars that can be activated with the touch of a button may be a good choice for kids who are unable to pedal or propel a foot-to-floor vehicle. However, such toys are expensive, and require constant supervision and regular battery recharges.

"These products were reviewed by the Oppenheim Toy Portfolio, an independent consumer organization that tests and evaluates the best products for children. The organization annually publishes THE BEST TOYS, BOOKS, & VIDEOS FOR KIDS; it also publishes a quarterly newsletter. Both publications include learning activity ideas and ways to adapt ordinary products for kids with special needs. To subscribe to the newsletter send \$12 to The Oppenheim Toy Portfolio, 40 East 9th, Suite 14m, New York, NY 10003."



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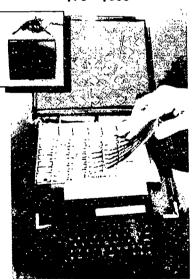
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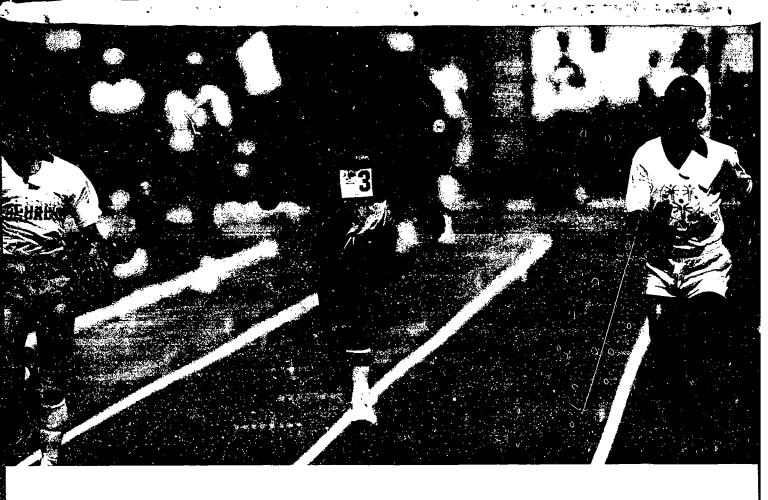
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Circle # 160

Talking With Your Child About Disabilities

by Chad Pierro

remember my first day of kindergarten because of the isolation I felt. I was used to getting occasional glances on the street, in the local shopping mail, or at the grocery store, but never had I experienced the intensity of the stares I got from my new classmates. Before this, it had been obvious to me that I was different, but this difference was magnified when I walked through the classroom door.

Having cerebral palsy has been a part of my life since I was born, but as a young child, my drsability was never really discussed. Maybe it was because I had no questions and just accepted things as they were, maybe because my parents didn't want to flood my mind with my physical condition—for whatever reason, we just didn't talk about it.

But when I came home from school that day, the questions came in a flurry—"Why was everyone looking at me? Why am I different from everyone else? Am I going to have any friends?"

I remember being comforted by my mother and father, but more than that, I remember getting answers to each question I asked. My parents laid things out for me in a clear manner that I understood; I was given practical ideas to deal with my feelings, and I was made to feel okay with the person I was. Once I rose above my insecurity, I was able to take control of the situations I later encountered.

It can be difficult to talk openly with your child about his or her disability or chronic illness. You don't want to make it the center of attention, yet you do want your child to understand his or her condition, as well as the different feelings and limitations that go along with it.

Few parents want their kids defined purely by a diagnosis. It is essential for children and teenagers with disabilities to be aware of specific issues that may affect their everyday lives so they are able to emphasive

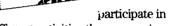
their personalities, not their disabilities.

You would be hard-pressed to find a child or teenager who enjoys sitting through a lecture given by a parent. Usually, lectures are seen as condescending sermons, not offerings of information. What works better is answering questions when they are asked, and suggesting ideas when appropriate. What is "appropriate" depends largely on your relationship with your child, but it is safe to say that occasional advice is more welcome than constant preaching.

Honesty is crucial in all parent-child relationships, and it is no less important when discussing disabilities with your child or teenager. So, when questions are asked—"What's wrong with my legs" or "Why can't I keep up in school?"—give answers that are understandable and truthful. Try to give complete answers because children can often sense when you are keeping things from them.

Some parents have the tendency to hold back information, wanting to spare their son's or daughter's feelings. What they fail to realize is that, in the long term, being given correct information at an early age is very good for healthy development. And, if kids are informed, they can answer questions themselves, rather than depending on Mom or Dad to speak up for them.

Learning about a disability or a chronic illness does not happen in a single session; rather, it is a process that continues over time. For this reason, it is often a good idea to encourage your children to



different activities they may enjoy. Children can be involved in summer camps, sports teams or school-related functions. A variety of experiences gives children and teenagers an idea of what they are able to do, as well as things they can do less easily.

Remember that, in many ways, children with disabilities develop similarly to children without disabilities. It makes sense then, to give kids information that helps them understand not only their differences, but also what they have in common with other children. With this knowledge, children with disabilities will be able to become comfortable with who they are, and who they can be. **EP** 

Chad Pierro grew up in the Twin Cities area of Minnesota. He is a graduate of Minnetonka High School and Augsturg College, with degrees in English (B.A.) and Psychology (B.S.). Chad works as a transition specialist for Project Youth, a program of the PACER Center, a Minneapolis-based family advocacy agency. In his work, Chad works with teenagers who have disabilities of all types and helps them work through the issues and difficulties they may be facing in their transition to adult life.

This article was adapted with permission from the Pacesetter, June 1994. The Pacesetter is a free newsletter published three times a year by the PACER Center. For a sample copy, send a 9 x 12 envelope with \$1.00 postage to the PACER Center, 4826 Chicago Ave. S., Minneapolis, MN 55417.



# READERS TALK ABOUT:

# Helping a Child Learn About His or Her Disability

A few months ago, we asked readers to share their experiences of talking with children about their disabilities. But as the mail started to arrive at our editorial offices, we realized the question we'd asked may have been too limiting. Most of the stories we read involved more than "talking"—indeed, in some cases, what parents did not say turned out to be more important than what they did say.

The parents who share their stories with us this month realize that learning about a disability or chronic illness involves more than a few conversations. Indeed, it will be a lifetong journey for both parent and child. For children, the process will certainly involve talking with parents, but it will also include discussions with peers, meeting adults with disabilities and having opportunities to take on new challenges in order to learn what they can do.

# **Following My Heart**

y children, Heather and Logan, were born with Miller syndrome, an excremely rare genetic condition which causes multiple physical anomalies including facial differences, shortened and bowed forearms, missing or webbed fingers and toes, and abnormal growth of the bones in the lower legs. Even after many years of living with children who have physical differences, I am still surprised at the situations that arise to remind me that my parenting experiences are very different

from those of others. Just when everything is going smoothly and my life starts to seem quite "normal," I find myself facing a problem I'm not sure how to handle...



Ready to open the gifts: (from left) Logan, 14, Debbie and Heather, 17, on Christmas morning 1994.

Playing basketball

When Logan was eight years old, he decided he wanted to play basketball. I didn't know how to react. His hands were so small and his fingers didn't straighten. How could he play basketball?

I have always encouraged both of my children to do all the things they wanted to do. I've tried not to discourage them because I don't always know what is possible. But if I encouraged Logan's basketball ambitions, he might get toohigh expectations, making the realities

of his limitations more disappointing. On the other hand, if I discouraged him, he might not try to achieve his goals in the future. I would never want him to give up without trying.

I called the coach and told him about Logan. He recommended that Logan come to the practice at which teams would be chosen. If Logan decided he wanted to play, the coach would work with him. If he decided not to play, at least he would have tried.

When the big night came, Logan lined

### **READERS TALK ABOUT:**

We invite you to contribute to the discussion in future issues of Exceptional Papers. In upcoming months, readers will be talking about:

- education options—special schools or inclusion? (September; deadline July 1, 1995)
- children's favorite toys and playtime activities (October; deadline Aug. 1, 1995)
- technology—how has it made a difference for your child? (November; deadline Sept. 1, 1995)
   grandparents/extended family (December; deadline Oct.1,1995)

Write to: Readers Talk, Exceptional Parent, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax). up with the other boys who were dribbling the ball up and down the floor. I could see it was difficult for him to control the ball, but he hung in there and completed the exercise. The teams were assigned and Logan ended up on a team with a couple of his friends.

Each week, Logan looked forward to the games. He always played in spite of his difficulties. But as the weeks went by, I could see he was becoming discouraged. He realized the other boys weren't passing the ball to him, and he knew it was because they were afraid he couldn't

catch it. His teammates were very nice to him and very supportive, but they wanted to win games.

Finally, it was the last game, the last quarter, the last minute of play. The ball ended up in Logan's hands. He jumped and shot. The ball went in. The crowd roared. Logan beamed. I felt so much happiness to see my son succeed.

The next year, Logan chose not to join the basketball team. I think he could sense the competitiveness of the boys his age. I didn't detect any regrets on his part, just calm acceptance of the way things were. I believe peace comes from acceptance, especially after you've given the situation everything you've got to give.

### The pageant

As girls reach junior high, they start receiving mail that would interest teenage girls. One day, Heather was excited to receive such a letter addressed to her. She opened it to find information about an upcoming Miss Teenage America Pageant. She read the letter and approached me with a beaming smile.

continued on page 94



# PARENTING

continued from page 93

She proudly told me she would like to enter the contest.

I felt an incredible pain in my heart. I didn't know if I should encourage Heather to enter a "beauty contest." On the other hand, I didn't want to tell her she couldn't try.

I asked Heather if she had read the qualifications for pageant participants. I pointed out the third rule which stated that participants must be in good health. Heather said she had read all the rules and felt she met that requirement because doctors always say she is healthy.

"Yes," I agreed, "you are healthy for someone with Miller syndrome. But are you healthy in comparison to people who do not have Miller syndrome?"

"Oh," she said, "when you put it that way, maybe not."

I suggested that Heather call the pageant director and tell that person

about herself. She immediately went to the phone. I told her to wait a minute because it was a long distance call and she needed to think about what she was going to say. I suggested she write out the questions she would ask and a description of herself.

A few minutes later, Heather returned. "This isn't going to work," she told me, "If I describe myself over the phone, the person will think I look like a freak!"

Again, my heart ached. I suggested she write a letter describing herself and send a picture. That way the person could see her too. She agreed this was a good idea.

A few days later, Heather came to me again. She told me she had been doing some more thinking and had decided against entering the contest. I asked her why. She replied that if she were watching a pageant like this one on television and saw someone who looked like her, she would think it was weird. After realizing that, she told me, she had decided not to enter.

I felt both relief and sadness. I was relieved that I didn't make the decision for Heather by discouraging her when she first approached me. But I was sad to think that because Heather looks different, she will not be able to do some of the things other teenage girls can do.

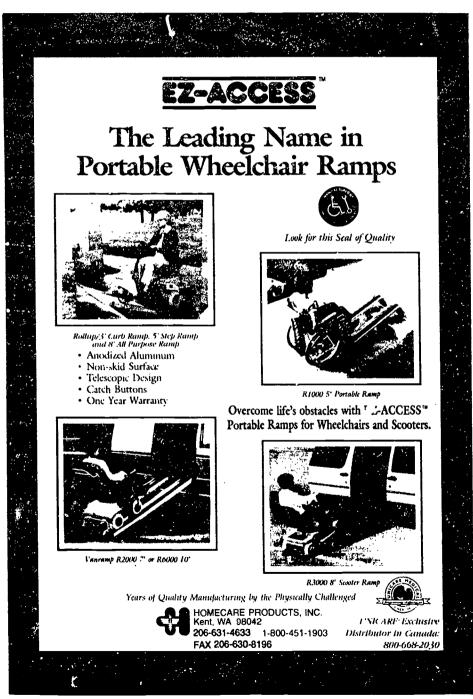
At the same time, I had to admire Heather for her courage and self-confidence. When I was her age, there would have been no physical reason to prevent me from entering a pageant. However, I never had the courage or self-confidence to even consider it.

## Proud of me, too

I am very proud of both of my children. And sometimes, I have to feel a bit proud of myself, too. I am glad I was able to follow the direction my heart took me when these situations came up in the first place.

--Debbie Madsen Salt Lake City, Utah

Debbie Madsen is a frequent contributor to ALL ABOUT ME, the newsletter of the Foundation for Nager and Miller Syndromes (FNMS, 333 Country Ln., Glenview, IL 60025; 800/507-3667). This article was adapted from two articles originally published in ALL ABOUT ME. For more information about Miller or Nager syndromes, contact FNMS.



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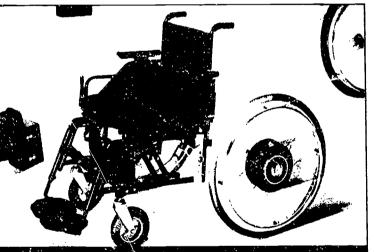
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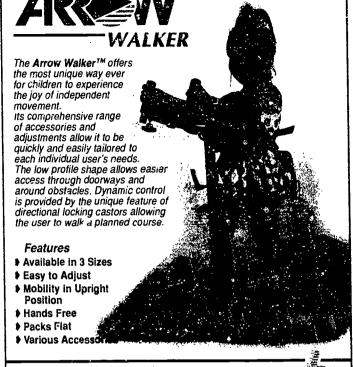
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Circle #72
JUNE 1995 / EXCEPTIONAL PARENT + 95

She Needed to See Winners

y daughter, Danielle, was born with spina bifida. Helping her accept her physical differences started at birth. People often asked, "What's wrong with . her?" We always started our answer by rephrasing the question—"Well, what is different about Danielle is..."

From the time she was little, we made sure Danielle was exposed to adults and other kids in wheelchairs. I also read her as many stories about wheelchair users as I could find.

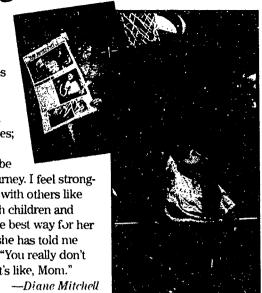
By the age of three, she knew she was different, but that difference didn't have a good or bad connotation. However, in kindergarten, Danielle started to think it was a bad thing to have spina bifida. Her classmates told her she would never get married and couldn't dance. She would come home from school sad and angry. I knew no words from me could change her negative feelings. She needed to see winners.

We started going to wheelchair basketball games. Danielle became involved in wheelchair tennis where she met lots of kids like herself. She also met married and working adults in wheelchairs.

Danielle is now nine vears old. She continues to ask questions and struggle with her differences: I know this process will be

a lifetime journey. I feel strongly that being with others like herself-both children and adults-is the best way for her to learn. As she has told me many times, "You really don't know what it's like, Mom."

Salem, Oregon



# Learning the "Ability Words"

alking to Jason about his disabilities came out of other people talking about Jason. Like in the grocery store, after Jason made a particularly loud remark about whether or not fish pass gas, a woman came up to me and said, "I know just what you're going through. We had one like him in our family too."

Later, Jason asked me, "Does that woman have a little boy like me? What does she mean? Like me. how?"

These situations were only compounded by educational and medical situations in which Jason was referred to as

moderately retarded, visually-impaired,

Jason (right) and older sister Jennifer enjoy themselves at a church party in 1993.

hyperactive, dysmorphic, seizure-disordered, multi-handicapped, even "syndromy." I had to ask myself, "What's a fella to think about himself while dodging all these 'diagnoses'."

I didn't feel fully prepared to tackle this ever-increasing army of adjectives aimed at Jason. So, over a period of time, I began asking everyone involved with Jason to tell me how they saw him, without naming one thing having to do with his disabilities.

I heard things like, "He's a hoot, a very funny kid; he's so observant--

notices the smallest things; his sense of smell is uncanny; he has remarkable recall; be has such curiosity; he makes me laugh." To me, these things were so much more Jason, and so much more important for Jason to learn about himself. My plan was taking shape-I wanted to start talking to Jason about his abilities, not just his diagnoses.

We began in the Wal-Mart parking lot, actually. While walking from the car to the store, Jason began his litary of smells nose down, sniff, sniff---"I smell diesel, road tar, oil, gas."

I replied, "Yes, you do smell them, Jason. You have a great gift of smell. Did you know that about yourself?"

Time after time, I identified Jason's abilities for him. I explained how these "ability words" were not in his diagnosis. and how the words that labeled him were not adequate to tell who he was but just said things about him.

The terrible taunts—called "teasing" by the people who do it—have been the hardest thing for me to help Jason deal with. It became my goal to disarm these labels and insults. "Some people only know the diagnosis words," I told Jason, "labels like 'retarded.' They haven't learned the other words that tell about you. You will have to be smarter than they are and learn the ability words."

And so, at a neighborhood Christmas party, as the adults gathered in the kitchen, we heard a child's voice from the den, "What's the matter with you? Are you a retard or something?"

The adults fell silent. Husbands and wives looked at each other, wondering whose child had slung the "R-word" at Jason.

But Jason was equipped to handle the situation. We heard him reply, "Retard, yes, absolutely. And I smell real good, too."

A roar of laughter arose from the den and spread through the kitchen. I did not attempt an explanation; it wasn't necessary. I thought to myself, "Jason is a hoot, a very funny kid—he makes us laugh."

> ¬Jan Moss Oklahoma City, Oklahoma

More READERS TALK on page 98

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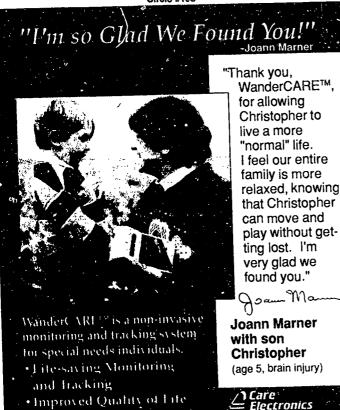
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# **Practice!**

ast Saturday, my husband, Rod, took our four-year-old daughter, Leah, to the grocery store. Leah has cerebral palsy and uses a wheelchair. She's very clever and funny—a real joy to be with.

She was watching a little girl about her age, when she suddenly turned to Rod and said, "Dad, I can't walk!"

It was one of those moments you dread, but Rod was ready. He bent down and kissed her and said, "I know, sweetie, but that's okay. We love you just the way you are."

I'm so proud of him, but not in the least bit surprised. You see, we've always talked about Leah's cerebral palsy with her. I can't figure out the parents who don't talk about a child's disability. Do these parents want to turn the disability into a subject that's too difficult or embarrassing to discuss?

I'll never forget my mother's attempt to talk to me about sex when I was 12. She couldn't look me in the eye and the whole ordeal was obviously so painful to her that I ended up in tears, begging her to stop! I don't ever want something as important as Leah's cerebral palsy to take on that "taboo" quality. Leah's disability is part of who she is and we embrace all of her. It's not a secret, or something we're ashamed of, so we talk, talk, talk until we're finally able to do so in a calm and sensible way.

A friend of mine, whose child also has cerebral palsy, can scarcely cough out the letters "C-P" without choking on them. That's not the message she wants her son to pick up on, so she asked me, "How do

you do it?"

I said, "Practice!" Tell everyone who crosses your path. Tell your neighbors. Tell your waitress. Tell the cashier at the grocery store. Only if it's a daily occurrence can you learn to talk about it matter-of-factly.

Practice talking about it with your child, especially while they are still



Taking a breather after some serious apple picking are (clockwise from left) Cara and Rod McCulley, Leah, 4, and Jake, 2.

young. I'm just as glad Leah won't remember some of my first awkward attempts. I don't recommend going overboard and beating it into the ground, but if the subject comes up—and it will—don't hide from it. Watch your child's reaction; you might be amazed to see relief when you explain why certain things are so difficult for him or her.

We are still learning about the impact Leah's cerebral palsy is going to have on our lives. But you can bet I'm going to include Leah in this process, every step of the way. And when people feel awkward about her disability or don't know what to say, I know that my kid-having talked about it all her life-will have what it takes to set them at ease. It's just a small part of our overall plan to teach Leah total self-awareness and acceptance, genuine selfesteem and the self-confidence to tell you all about it.

> -Cara McCulley Johnson City, New York





# Star of the Team

ctodermal dysplasia (ED) is a genetic condition involving abnormalities of the ectoderm (skin and its derivatives). There are many types of ED; our son, Kyle, is affected with hypohidrotic ED. Kyle has a total lack of sweat glands, total absence of teeth (he's worn a full set of dentures since age two) and sparse hair follicles

(last year, he finally had enough hair to get his first "trim").

Kyle's inability to sweat results in heat intolerance and fevers of unknown origin. Most of these episodes may be avoided by environmental adaptations—staying in air conditioning, finding shade and, when necessary, wetting him down with cool water

Our family has always had a rule that you must be 10 years old to play football. Last fall, Kyle turned 10 and, you guessed it, he really wanted to play. Kyle already plays baseball and basketball in organized youth sports programs. I told him he could try football, too, but reminded him it would be very difficult for us to keep him cool under all that equipment.

He insisted he wanted to play, so we told him to go for it. On the day of the first football practice, the weather was sunny, hot and almost unbearably humid. Kyle and his dad set off for practice with four gallons of water.

Kyle came home three hours later, totally soaked but with a smile on his face. "How was practice?" I asked.

Kyle replied that he had discovered football was not his sport. Mind you, he was smiling. For the first hour and a half, he had happily performed all the tasks the coach requested—sprints, monkey rolls and other drills. F next half hour, he performed all the tasks the coach requested with tears in his eyes. And for the last hour, he sat on the sidelines, totally wet, watching the team.

That day, Kyle learned a lesson we all must learn at some point in life—there are some things we can do and there are other things we want to do, but can't. Kyle told me he was really glad he had tried to play football and that someday, when he is older, he will try again. But, he added, even if he doesn't ever play football, it's okay because he is good at basketball and baseball.

I am proud of Kyle because he tried his hardest to do something he wanted to do. I am proud of us, his parents. because we let him try. All in all, it turned out to be a great day. In my mind, Kyle is the star of that football team and always will be.

-Pam Spilbeler Bloomington, Indiana

For more information about ED, contact The National Foundation for Ectodermal Dysplasias, 108 N. 1st St., Ste. 311, Mascoutah, IL 62258, (618) 566-2020.



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Circle #163 JUNE 1995 / EXCEPTIONAL PARENT . 99

What's in a Name?

ne day recently, I was driving the eternal

Best friends
(from left) Robin Holmes,
Mollie Hanson and Katie
Baesemann enjoyed lunch at
a Chicago restaurant during
a day trip to the big city with
their moms. They also took
in a theater performance of
Joseph and the Amazing
Technicolor Dreamcoai.

carpool to ballet with three teenagers in my back seat. All three girls have cognitive disabilities and have been in classes together since preschool. They enjoy adult interaction, in spite of the fact that they are teens, but I take a stance of "benign neglect" while driving, letting them sit in the back seat together

and relate to each other. My ears perked up, however, when my daughter, Mollie, started talking about her syndrome. It came out of the blue.

"I have CVS [cyclic vomiting syndrome]," she announced and gave a sentence or two of explanation to her friends. "What do you have, Katie?"

After a moment to think and a bit of a prompt, Katie answered, "I have Williams syndrome." A few sentences of explanation followed with just a little assistance from me.

Then Mollie turned to Robin, who has Down syndrome. "What do you have, Robin?"

Robin's reply was immediate and despondent—"I have diarrhea!"

Luckily, I maintained control of the car as I squelched an enormous laugh. How lucky I was to be at the right place at the right time to hear this personal, matter-of-fact conversation. I again realized, in a vivid way, that much of the time, my daughter and her friends don't need labels or definitions. What they do need is ongoing care and concern in learning to deal with issues as they arise—the "issues of the moment." Robin's issues as a person living day-to-day far outweigh her need to have a named syndrome.

-Kathleen Adams Elm Grove, Wisconsin

Cyclic Vomiting Syndrome (CVS) is a rare, unexplained disorder of children and some adults. The condition is characterized by recurrent, prolonged attacks of severe nausea and vomiting. Vomiting may occur five to six times an hour; an episode typically lasts one to four days. Mollie's cognitive disability is unrelated to CVS. For more information on CVS, contact the Cyclic Vomiting Syndrome Association, 13180 Caroline Ct., Elm Grove, WI 53122; (414) 784-6842, (414) 821-5494 (fax).

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Circle #238

# **Getting Off to a Good Start**

Helping your child make the transition to a new school year

by Jeannie Lancaster

t's only the beginning of summer, but fall—and the stan of a new school year—will be here before we know it. For many children this means a move from elementary to middle school (or junior high), or from middle school to high school. These changes are exciting but can also lead to anxiety and uncertainty. This is especially true for a child with special needs who has difficulty adjusting to change.

Our two sons, now 18 and 15, 're both affected by fragile X syndrome. (For more about fragile X syndrome, see Ask The Doctor; page 117.) In spite of their common diagnosis, each boy handles change differently. Our youngest son's excitement over upcoming changes often results in hyperactivity and hand flapping. He is more social than his older brother and looks forward to new situations, but his physical behavior shows that he still feels apprehension. Our older son, who has a severe anxiety disorder, shies away from all new situations, panicking over the idea of new sched des, new teachers and new expectations.

Although the boys are very different in their approach to change, there are some things we have done through the years that have helped make transitions easier for both of them.

### Things that have helped

 Picture scrapbook: I came upon this idea in an unusual place. I was reading a brochure from a moving company on ways to make moving to a new home easier for small children. One suggestion was to take pictures of the child's new home. city, schools and neighborhood, and place these pictures in a scrapbook for the child. Wow! I realized a scrapbook of this type might also be helpful for a child with special needs who was moving to a new school.

That spring, during the last few days of school, I headed off to the middle school my son would be attending in the fall, with camera in hand. I darted about the school taking pictures of teachers my son would have, the principal, the lunchroom, classrooms, the library and, yes, even the bathrooms. I'm sure there were a few people who thought I was a little crazy but it proved to be a good idea. Together, my son and I put together a scrapbook of pictures. During the summer we looked at the book and talked about the school.

 Walking through the schedule: Getting an advance copy of your child's schedule can also be helpful. Before school begins, you can try to set up a couple of times when you and your child can walk through the halls, learning the routes to



Getting together before school started helped both Sean and his earth science teacher, Tom Hewson, feel more comfortable about the coming year. The science department's pet iguana joined their meeting.



and son Sean look at a scrapbook containing pictures of the school Sean will attend the next fall.

and from classes. This will also allow the child to become accustomed to the school at a time that is free of excessive noise and other disruptions. Another idea—even more positive—would be to have an older peer, who will attend the same school, walk through the schedule with your child.

It's helpful to have the need for an early schedule written into your child's IEP (Individualized Education Plan). This year, our local high school announced a plan to hand out final schedules to all sophomores, juniors and seniors—all 1,300 of them—on the first day of school. But because our sons' IEP's specified that they be allowed to walk through their schedules

before the start of school, we were able to get their schedules over the summer and avoid a potentially overwhelming situation.

• Getting acquainted with teachers: Advocating for our sons' inclusion in as many regular classes as possible has resulted in an increase in the number of teachers who serve them. This is especially true in middle school and high school. In an effort to help the teachers who will be working with our sons, we write notes introducing ourselves and our sons and send them to the teachers before school begins. We include information explaining fragile X syndrome and request a time when we could stop by to have our boys



... 558



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# Getting Off to a Good Start



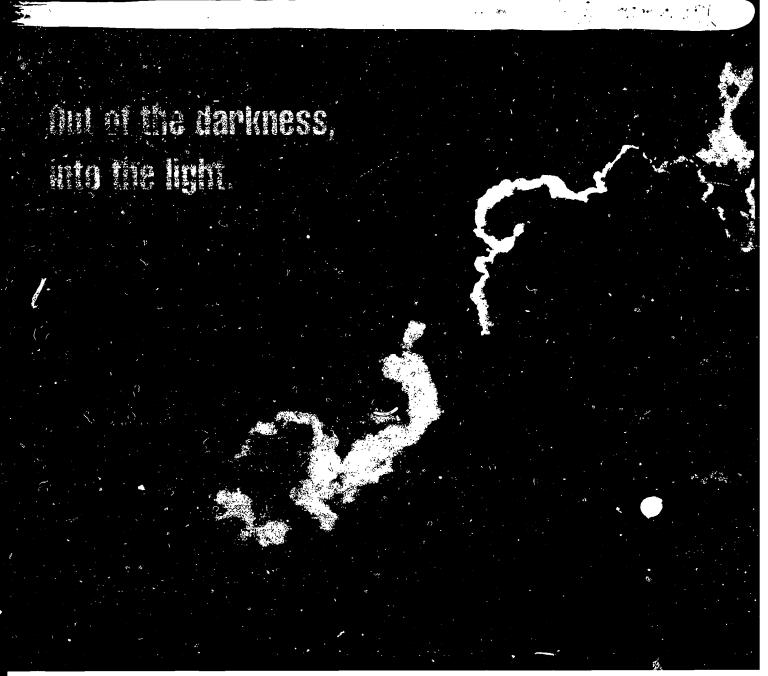
Stopping by to meet and greet members of the school administration is another good idea. Here Sean and his father, Dave, get acquainted with assistant principal Jana Frieler.

meet them. When we visit, we stay just long enough to say hello, shake hands and allow our boys to put a face with a name. This seems to make the transition on the first day of school a little easier. We've found most teachers to be extremely responsive to this approach and feel it has been a good start toward building a positive working relationship with them.

- Other ideas: Other things can be done to assist a child as he or she moves to a new school or begins a new school year. For example, make sure your child knows how the lunch program works in his or her school. Familiarizing the child with the bus schedule might also be helpful. Perhaps most important is for the parent to convey a positive attitude about school. These things don't take a lot of time, but they can make a big difference.
- Keep in touch: Too often, parents have contact with a child's school only when there are problems. It is also important to let teachers know when things are going well. Occasionally writing a note, thanking a teacher for the things that are working and letting them know you appreciate their efforts, can make a positive difference.

We cannot, nor should we, remove all obstacles in our children's lives. But there are some simple things we can do to make new situations less threatening and help the school year get off to a better start. This can be extremely beneficial for children who are challenged by anxiety in new situations. Some of these things take a little extra time, but the rewards far outweigh the sacrifices. **EP** 

Jeannie Lancaster lives in Loveland, Colorado with her kusband, Dave, and three children, Torri, David and Sean, all of whom have fragile X syndrome. Jeannie is a full-time student, part-time freelance writer and full-time advocate for her children's inclusion in all aspects of life. She has served on the board of directors of the National Fragile X Foundation and currently coordinates a local program called Loveland Oral Readers for Education (LORE) in which volunteers record books for students with reading delays.





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# Children's Health Notes



# How Culture & Ethnicity Affect Health

How individuals think—their beliefs—influence the course of life events. For families and children living with chronic conditions, their beliefs can influence the meaning of the condition and shape the development of coping strategies.

These beliefs may even determine whether or not the family seeks medical help.

Still, little is known about the different cultural meanings of chronic illness and disability from the family's perspective.

Researchers from the
Center for Children with
Chronic Illness and
Disability collaborated
with researchers at La
Rabida Children's
Hospital and Research
Center and were
awarded a grant to study
the range of meaning
that African, Hispanic,
and European American
families give to having a
child with a chronic
illness or disability.

The fact that farnilies living in the United States in the 1990s are influenced by many cultures simultaneously make a multicultural approach preferable.

"What might be interpreted as cultural differences might really be a function of the family's economic situation or other circumstances," says Ann W. Garwick, Ph.D., researcher and clinician.

The purpose of the project is to:

- Identify the range of meanings that families give to having a child with a chronic illness or disability;
- Describe the impact of chronic conditions on families;
- Compare how families and primary care physicians view the impact of caring for a child with a chronic condition;
- Involve community leaders and members in the research project;
- Develop a theory and hypotheses on the influences of perceptions of childhood chronic illness and disability.

"One goal of this project is to better understand how culture influences a family's understanding of health, illness and disability so that health care providers can provide care that is culturally sensitive and pertinent to the needs of children and families from diverse backgrounds," Garwick says.

# **DEFINITION**

# Culture ...

Reflects the various differing values we place on our daily activities.

**DEFINITION** 

# Ethnicity

Group consciousness based on a sense of common origins, a sense of peoplehood.

# Children's. Health Notes

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**Communities Take the Lead** 

You'd think the easiest way to identify families to participate in this study would be to ask the doctors that see them.

That may be the easiest, but it may not be the best, especially when you're trying to clarify how cultural differences influence the way families understand their child's chronic illness and disabilities, especially when you want to be able to help

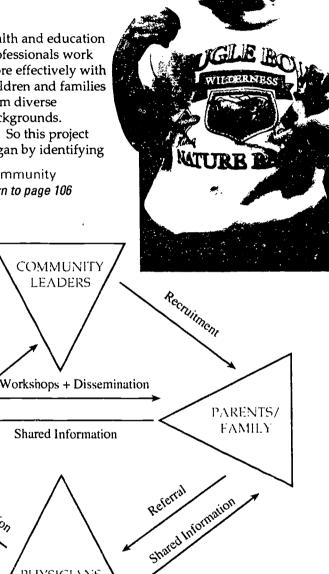
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RESEARCHERS

health and education professionals work more effectively with children and families from diverse backgrounds.

So this project began by identifying

Community Turn to page 106



# Relationships Among Researchers & Participants

PHYSICIANS

This diagram shows how researchers have established a collaborative relationship within the communities we are studying and reflects the complex web of relationships necessary to conduct research. Still, few arrows connect the families to the communities in which they live. Clearly, community agencies need to develop strategies to connect with families to decrease their isolation.



Shared Information

# Community From page 105

leaders in communities we wanted to study-African Americans, Hispanic Americans, and European Americans—to help us define, design, and pilot the study. And we asked them to help find willing participants. "What's interesting," Ann Garwick, one of the investigators, says, "is that while community leaders have been genuinely enthusiastic in reviewing questions and training (or becoming trained as interviewers), they had trouble finding families."

The leaders sought referrals from parents of children with disabilities through community groups such as boys and girls clubs, neighborhood community centers, parent support groups,

...regardless of ethnicity and culture, families said they felt isolated...

religious groups, and YMCAs. And while they were able to recruit 58 for the study, recruitment has taken longer than expected.

Identifying children with disabilities and their families was challenging for the community leaders and took longer than the investigators

planned. Given this experience, it should come as no surprise that early analysis of the interviews suggest that, uniformly and regardless of ethnicity and culture, many families said they felt isolated. Some say they feel this isolation because they have had to search so hard to find information on their child's condition or on the services available. Some feel that they have to advocate at every turn in their life. They say that programs don't exist in the community, rather,

families have to ask for, and often start, appropriate programs. Still, some families report that they never see other families like themselves. Each of these signals that, while communities might be a wealth of support for some families, most community leaders and organizations are challenged when it comes to even identifying who, in their community, is raising a child with a chronic illness or disability.

With the interviewing complete, researchers have developed both the conceptual framework and the coding scheme for analyzing the family interviews. "Investigators at both sites have been reviewing the verbatim transcripts," Garwick says. Such analysis is time-consuming. Once the transcripts are coded, Garwick and her team review the material to identify what influences are specific to unique cultural perspectives.

How can we eliminate a family's sense of isolation?

Garwick says clear information should be provided not only to families but to the local churches, YMCAs, community centers, schools, day care programs and clinics. But that is just a start. Do you live in a community that has succeeded in integrating your child with a disability and your family in some way—large or small? What are some of the ways families feel less isolated, more connected to the community? Please let us know.

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When Physicians Talk to Parents:

# **Learning What Families and Physicians Share**

Families know what they want and what they need. Regardless of ethnicity or culture, most families report they are satisfied when they feel they've been heard. They are satisfied when their concerns and ideas are valued and acted upon.

C3ID researchers are also interested in what physicians say and know about the impact of culture and ethnicity on the health of children with chronic illness and disabilities and their families. The physicians for each family involved in the project will be interviewed and will provide additional input.

A set of questions that would be appropriate for physicians was selected from the family interviews. The goal is to get at how physicians understand the family with a chronically ill child, their culture, support system and general coping process. Researchers will then compare the family and physician's points of view.

When we analyze the data, we are looking for recommendations that families and physicians have for improving care for children with chronic conditions from diverse cultural backgrounds.

"When we practiced the interview questions with physicians," Garwick says, "they felt the questions were clear and relevant." The questions themselves raise the physician's awareness of family and cultural issues. "Most are interested in getting feedback. One physician said, 'if you discover anything you think might impact on the way I interact with a family, or can help the family, please share it."

Physicians are also asked to complete scales similar to those to which

families respond. The Characteristics of Chronic Conditions Scale includes questions about the child's type of chronic illness and treatment. This scale has been developed by a team of C3ID investigators. The questionnaire will provide data about chronic conditions that can be used to interpret issues and themes in family interviews that are related to the nature of the condition.

Like the families, physicians also respond to the "impact on Family Scale." This scale tries to assess how a child with a chronic illness or disability affects a family. Does it cause financial problems? Have parents had to leave work? Take on extra work? Are they tired much of the time? Do



families feel closer? Both the physicians and the families indicate the degree to which they believe statements are true or not true. Physicians can also answer "don't know."

# The Center for Children with Chronic Illness and Disability

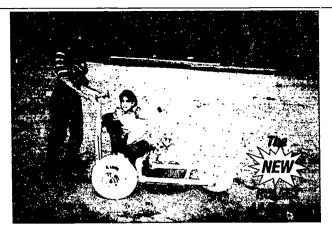
was established in October, 1989, and is housed at the University of Minnesota. The organization is a research and training center dedicated to the study and promotion of psychological and social well-being of children with chronic conditions and their families.



# MISSION

The Center for Children with Chronic Illness and Disability is learning a great deal about children with chronic illness and disabilities, their families, and the political, health care, and policy environments that affect their care. To reach as many families as we can, we join with Exceptional Parent to publish Children's Health Notes to define the environment, raise questions, identify strategies, or provide clarification of issues that are critical to providing care for children with special needs and their families.





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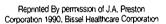
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# HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

# The Katie Beckett Waiver

We own our own home, and our income puts us over the limit for Medicaid coverage. We have always raised our child at home, even though health care professionals have suggested institutionalization.

If our child was in an institution, the government would pay all the costs, including medical care. Since we have kept our child at home, however, the government will not pay for any of the costs. In fact, the government will not even pay for basic medical care. Is there anything we can do?

Although the Medicaid regulations that apply to income limits seem quite rigid, there are some exceptions to those regulations. These exceptions are known as "waivers." Each waiver represents a situation in which specific states have applied for, and have been granted, exemptions from the standard Medicaid rules.

One of the most important of these Medicaid waivers is generally known as the "Katie Beckett waiver" or the "Katie Beckett provision." In the early 1980s, when the Katie Beckett waiver was first established, if a child with a disability lived at home, Medicaid generally considered parents' income in evaluating the child's eligibility. If the child was hospitalized or institutionalized for an extended period, however, the parents' income generally was not considered.

Katie Beckett, a young child who was on a ventilator, was unable to go home from the hospital, not because of medical reasons, but because she would no longer have been eligible for Medicaid. While Medicaid rules allowed for the continued payment of hospitalization costs, they did not allow Medicaid to pay for the cost of home care, even though home care would have been far less expensive.

Eventually, a special Medicaid waiver was created so that Katie Beckett could return home. Since that time, the Katie Beckett waiver has helped an enormous number of children who would have been forced by Medicaid regulations to remain permanently in hospitals or institutions.

# State regulations

Since Medicaid is administered at the state level, the Katie Beckett waiver is available only to residents of those states that have adopted it. Although almost every state has some form of the Katie Beckett waiver, regulations may differ drastically from state to state. Contact your state Medicaid office to learn the details of your state's waiver.

According to the National Health Law Program, a child with a disability does not need to be institutionalized to qualify for the Katie Beckett waiver. Thus, depending on the state you live in, and the specifics of your child's disability, the waiver may be applicable to your situation.

The specific rules are complex. In general, however, the waiver may apply to a situation involving a child with a disability under 18 years of age, for whom home care is appropriate, and in which the child requires a level of care

equivalent to that provided by an institution. In addition, the cost of home care must be less than or equal to the cost of institutionalization. The waiver is available only to children who would qualify for Medicaid if institutionalized. There are other specific rules, as well.

In states that have n t adopted the Katie Beckett waiver, Medicaid will consider paying the costs of long-term institutionalization for a child with a disability, regardless of the parents' income. However, even though the state would have to pay the full costs if the child were institutionalized, those state Medicaid programs generally will not pay any medical costs for a child with a disability if he or she is being cared for at home, unless the parents' income meets Medicaid eligibility requirements.

### If denied

If your Medicaid application has been denied, and you think you qualify under a Katie Beckett waiver or under a different waiver program, contact your local Protection and Advocacy office or the local legal services office for advice. For your local offices, contact the National Legal Aid and Defense Association. 1625 K St., NW, Ste. 800, (202) 452-0620 (voice), (202) 872-1031 (fax).

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303. Brookline, MA 02146, (617) 730-8742 (fax).



If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

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Irene Pollin, author of TAKING CHARGE:
OVERCOMING THE CHALLENGES OF LONG-TERM
ILLNESS, is a parent and psychiatric social worker. In dealing with her children's illnesses, Pollin became aware that professionals receive scant training to help individuals and families cope

with long-term effects of chronic illness or disability. Neither mental health nor medical specialists provided the support she and her husband needed.

Although Taking Charge: Overcoming the Challenges of Long-Term Illness was written specifically for individuals with long-term illnesses, every chapter is filled with powerful information and helpful support for parents and other family members. Here's what nationally-syndicated columnist Ann Landers says about Taking Charge: "[This] book... should be required reading for everyone facing the challenge of long-term illness, whether their own or that of a loved one... It could be the most valuable gift you will ever give."

In Pollin's words—'I have discovered that by confronting and taking charge of your fears, you can learn to accept your [or your loved one's] long-term condition. Indeed, you can once again take charge of your life." TAKING CHARGE is available from Exceptional Parent Library (800/535-1910). The following is an except:

# **Face Your Fears**

Many people worry that if they confront their fears, they'll fall apart or lose control. In truth, all of us wish to be secure in what we know we can count on. It feels safe and reassuring to have a sense of control. However, it doesn't follow automatically that if you're frightened or unsure of what's in store you'll be out of control.

Every day, uncertainty slips into our lives. Neither a salesperson nor a department store buyer knows in advance how many items they'll sell, yet they order merchandise. A restaurateur shops for and prepares meals by predicting how many patrons will order roast beef or fish or lasagne in a given evening—but he never knows for sure. There is an expectation of certainty, but in fact no one is certain the expectation will be fulfilled.

While we can conduct business tolerating a measure of ambiguity, we find it hard to apply these principles to our health. We want to be sure we are healthy yet we can never really be completely confident. What goes on within our bodies is often invisible to us. We don't recognize a problem until it becomes a bleeding ulcer or shortness of breath. In truth, we live with uncertainty all the time, yet we maintain control of our lives.

Nevertheless, "fear of falling apart" pushes people to keep their other anxieties inside, even when it means going against their natural tendency to face them and express themselves openly. For example, Emily, one of my young patients from Chicago, became uncharacteristically silent after a diagnosis of multiple sclerosis. Her husband felt so uncomfortable with her atypical demeanor that he finally screamed at her, "For God's sake, Emily, you've got MS. Where's your reaction?"

All her life, Emily had prided herself on her ability to communicate. Now, however, she feared losing control if she verbalized her terrifying thoughts: "Will I end up in a wheelchair?" "Will I be able to have children?" "If I do have kids, will they have to care for me or make the decision to put me in a nursing home?" Once she allowed herself to voice these terrible but understandable fears to herself and her husband, not only did she feel more stable emotionally, but she was able to make decisions about her life that eased her adjustment to her new situation...

You [can] face and resolve your fears by examining the most salient ones in detail. One fear—what I like to call the "ninth fear"—asserts that you're making up all the others. This attitude can undermine your ability to accept your other anxieties as legitimate. When you succumb to it, you don't permit yourself to be serious about or respectful of your own needs.

Let me assure you that even though in the past some of your fears may have been unfounded, today they are valid. They're based on real problems. If you're anxious that a surgical procedure is dangerous, it probably is. If you're worried about the long-term side effects of a medication, you probably have good reason. In fact, x you make your own medical decisions, you'd be remiss if you didn't consider the consequences carefully. Your worries, therefore, aren't imaginary. They are compelling and should never be dismissed.

Some people fear that their feelings during this vulnerable time are "irrational." In truth, emotions are never rational or logical—they're emotions. Moreover, given the high state of anxiety that chronic illness provokes, it seems perfectly normal to feel irrational at this time. Emotions and actions are distinct, however. Feeling irrational does not mean that you'll act irrationally.

A final note: It's important to recognize that your worst fear may never come true. Since the course of most chronic illnesses is unpredictable, your situation could improve rather than worsen, as in the case of one distraught woman who had checked into the hospital to undergo risky surgery for the removal of a tumor in her neck. During the final pre-operative exam, her surgeon discovered that the tumor had shrunk and surgery was no longer necessary. Until that moment, it had never occurred to this woman that she would be spared the operation!

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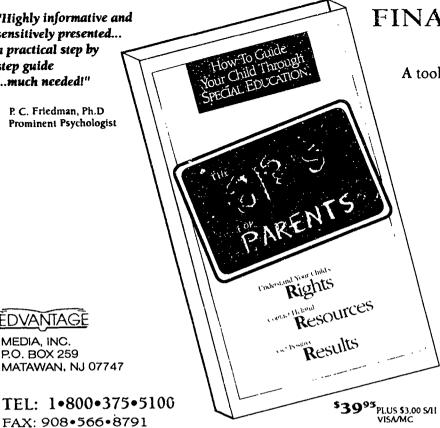
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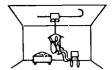


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# Networking

# Information from The National Parent Network on Disabilities

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Holding young reception attendee Akison Sparks, Sen. Bill Frist, R-TN, chairman of the Senate's Disability Policy Subcommittee, reaffirms his commitment to people with disabilities at NPND's second annual congressional reception.

# **NPND Congressional Reception**

The National Parent Network on Disabilities (NPND) held its second annual congressional reception March 13 to honor parents of children with disabilities. Senate Majority Leader Bob Dole, R-KS, sponsored the event.

Sen. Bill Frist, R-TN, chairman of the Disability Policy Subcommittee of the Senate Labor and Human Resources Committee, reaffirmed his commitment to work with families to improve programs for people with disabilities. He extended an invitation for people to participate on his teans, and to work with him during these challenging times.

Other legislators attending the reception included Sens. Nancy Kassebaum, R-KS; Tom Harkin, D-IA; Paul Wellstone, D-MN; and Christopher Dodd, D-CT; and Reps. William Goodling, R-PA; Major Owens, D-NY; Steny Hoyer, D-MD; George Miller, D-CA; and David Hobson, R-OH.

Also during the reception, NPND's Distinguished Service Award was given to Diana Cuthbertson, former president of NPND's board of directors. Cuthbertson was recog-

nized for her tireless work on behalf of parents and children with disabilities.

NPND thanks the organizations and individuals who helped make this reception a success: Parent Training and Information Centers, members of the Consortium for Citizens With Disabilities and the individual NPND members who contributed financial support for the event.

# **Legislative Update**

With its first 100 days behind it, Congress took a recess beginning mid-April. It left behind a trail of legislative setbacks and attacks on people with disabilities. Upon its return, this assault on the rights of people with disabilities was expected to continue.

# SSI CHILDREN'S BENEfits

The House of Representatives passed the Personal Responsibility Act (PRA), a bill with provisions that would save federal dollars by eliminating 250,000 children from the SSI (Supplemental Security Income) program, which provides funds to people with low incomes and limited assets who are 65 or older or who have disabilities. If PRA is passed by the full Congress, the savings will be passed on to the states as block grants. Children and adults who lose their federally-administered SSI benefits

continued on page 116



NPND executive director Patricia McGill Smith (left) presents Diana Cuthbertson, past presiderit of NPND's board of directors, with the NPND Distinguished Service Award at the congressional reception. In the foreground are Joanne Butts, NPND president, and Cuthbertson's husband, Hank.

# **Volunteers Needed for Media "Swat Team"**

NPND, in conjunction with other disability advocacy organizations, is forming a national Media Swat Team. This team will keep track of reports in the media that are damaging to people with disabilities and issue replies as swiftly as possible. If you are interested in volunteering as a media monitor or writer, contact Larry Searcy, NPND, 1600 Prince St., Ste. 115, Alexandria, VA 22314, (703) 684-6763 (V/TTY), (703) 836-1232 (fax).



continued from page 115

can apply to their states and may receive benefits

that each state decides to provide.

Under PRA, those not eliminated will continue to receive cash payments from the federal government as long as they qualify. However, cash payments will be phased out because all new SSI applicants will have to apply to their states.

The House bill also eliminates the "individual entitlement" component of SSI benefits. This means that even if a child is deemed "eligible" for benefits, the child will not be "entitled" to receive services. Waiting lists for recipients will be developed and services will be delivered on a firstcome-first-served basis.

NPND had been told that the Senate is likely to uphold the provisions of the House bill. As Exceptional Parent went to press, however, NPND had just been told that Sen. Kent Conrad, D-ND, was expected to introduce a Senate alternative to the House approach that would be much more favorable to children. Details were not known as of press time.

# REAUTHORIZATION OF IDEA

As Exceptional Parent went to press, the Senate leadership was pressing for a one-year extension of the Individuals with Disabilities Education Act (IDEA) to ensure that none of IDEA's funds would expire at the end of this fiscal year, September 30.

The Senate had planned hearings on IDEA for May 9, 11 and 16. In June, the Senate intends to hold staff briefings on IDEA for staffers of the Senate's Disability Policy Subcommittee. According to the Senate calendar, a draft bill will be produced in August or September. Hearings will then be held on the draft bill with floor action expected in October or November.

The House had planned to participate in a joint hearing with the Senate on May 9 and was to hold its own hearings May 16. House staff have indicated that they will aim to produce a draft bill by early summer with floor action by the end of September.

# HERFTAGE FOUNDATION CALLS FOR ELIMINATION OF EDUCATION DEPARTMENT

The Heritage Foundation, a leading conservative think tank, has called for the elimination of nine presidential, cabinet-level departments. According to an April 17 press release, the group has proposed reducing the number of such departments from 14 to five. Some would be consolidated, others would be reduced to sub-cabinet independent agencies, while others would be completely eliminated with responsibilities shifted to states.

NPND is concerned because the group has proposed closing down the Department of Education, "though some of lits! functions, as part of the overall streamlining and consolidation process, would be shifted to the states or moved elsewhere within the federal government." The group has not indicated what would happen to special education programs under this proposal.

# **Ed Roberts** 1939-1995

E d Roberts, the father of the inde-pendent living movement for people with disabilities, died in March at his home in Berkeley, California. He was 56.

We have lost one of the greatest leaders of our time. Ed was a monu-

mental role model, teacher and advocate for parents and children with disabilities.

As a result of polio at the age of 14, Ed was paralyzed from the neck down and left with motion in only one finger. He was ventilator-dependent, and slept in an iron lung. Ed was the first student with severe disabilities to attend the University of California at Berkeley.

In 1972, Ed co-founded the Center for Independent Living (CIL) in Berkeley. CIL became a model for more than 400 similar centers worldwide run by and for people with disabilities. Ed went on to head California's State Department of Rehabilitation and to co-found the World Institute on Disability, a public policy, research and training organization, with Judy Heumann. In 1984, Ed received a prestigious MacArthur Foundation "genius" award.

Recognizing Ed's loss, Pres. Clinton eulogized: "As an international leader and educator in the independent living and disability rights movements, he fought throughout his life to enable all persons with disabilities to fully participate in mainstream society... Mr. Roberts was truly a pioneer... His vision and ability to bring people together should be an example for everyone."



On June 22, NPND, along with the Spina Bifida Association of America and other disability organizations, will stage a rally on the West Steps of the U.S. Capitol Building in Washington, DC. The rally will be held from noon to 2 p.m. Speakers will include lawmakers and leading national disability advocates. Entertainment and refreshments will be provided. After the rally, participants are being urged to lobby their senators and representatives.

Members of Congress often say they are do not hear from the disability community. Let's make a statement that they won't soon forget. For more information, contact NPND, 1600 Prince St., Ste. 115, Alexandria, VA 22314, (703) 684-6763 (V/TTY), (703) 836-1232 (fax).

# Join the Family Action Network (FAN)

Please complete and return this form to NPND to join FAN. FAN Alerts and newsletters about important leg-Islation and other information will start arriving as soon as your subscription is received by NPND.

This is most important as IDEA is up for re-authorization. FAN members will receive quarterly newsletters with updates on how IDEA is faring in Congress. Alerts of timely information and requests to take action to save IDEA will be sent when necessary.

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# ASK THE DOCTOR

by David Hirsch, M.D.

# Fragile X Syndrome

Our son is seven years old. We know he is mentally retarded and, according to his pediatrician, he has some features of fragile X syndrome. He has had a number of diagnostic tests, including chromosome tests. All have been "negative." Our family has no history of mental retardation or any other genetic diseases. We do not want our son to go through any unnecessary testing. Do you have any suggestions? If he does have fragile X, is there anything else that can be done?

A Fragile X syndrome is the most common cause of inherited mental retardation. It occurs in approximately one in 1200 males and one in 2500 females.

Fragile X syndrome is called an "X-linked disorder" because the FMR-1 gene, the gene responsible for fragile X syndrome, is located on the X chromosome (one of the sex chromosomes; the other is the Y chromosome which only males carry). A woman who carries the gene for an X-linked condition has a 50-50 chance of passing it to either a son or daughter, since she contributes one of her two X chromosomes to each child. A man with the same X-linked gene passes it to all his daughters (they all receive his X chromosome) and none of his sons (they all receive his Y chromosome).

The severity of fragile X syndrome in an affected individual is usually related to the size of the DNA mutation within the FMR-1 gene. Some intellectually normal people have a fragile X "premutation," or small mutation. These premutations are unstable and can expand in size when passed from mother to child. If the premutation expands to the size of a full mutation, the FMR-1 gene "turns off" and does not work properly. Of the females who carry a fragile X mutation, approximately 33 percent will show some symptoms; in males with the mutation gene, roughly 80 percent will have some degree of learning and behavioral problems.

Common physical characteristics of fragile X syndrome may include a long, narrow face; prominent forehead; prominent, square chin; large ears; a flattened nasal bridge; a high, arched palate (roof of mouth); a relatively large head and large testicles. These facial features tend to be more noticeable in adults than in children, and in males more often than females. Many children with fragile X who are younger than six do not differ greatly in appearance from other children.

Males with fragile X syndrome usually have mental retardation varying from mild to severe, with the majority of affected males within the moderate range of intellectual disability. The vast majority of individuals with fragile X, especially males, will have developmental delays (most commonly speech delays), poor gross motor coordination and, sometimes, autistic-like behavior.

Your son may have some or all of these characteristics to a varying degree, but a definitive diagnosis of fragile X syndrome can only be made by more sophisticated genetic testing. specifically "direct DNA analysis" that looks for the presence of a very specific piece of DNA within the FMR-1 gene. It is very possible that the routine chromosome tests already done on your son (sometimes called cytogenetic testing) might not detect fragile X syndrome. Direct DNA analysis is done with a small sample of blood sent to a lab that has expertise in this area of genetic testing.

I certainly agree that your son should not have any unnecessary testing. However, if he does have some typical physical features and/or behavioral characteristics of fragile X syndrome and the cause of his mental retardation is not yet known, even with the negative family history, I believe it would be worthwhile to have a comprehensive genetic evaluation and

appropriate DNA testing done. When a definitive diagnosis is obtained, it is easier to plan for a child's future, design appropriate educational programs and find parental support groups. The blood test should not be very painful, however, the cost may be significant.

No medication or other treatment has been shown to be absolutely effective for individuals with fragile X syndrome. Folic acid supplementation has been tried, but I do not believe there is any clear evidence regarding its effectiveness. Speech, occupational and physical therapy, as well as the most appropriate educational environment, would be required to assure your son's optin al development.

For more information about fragile X syndrome contact FraXa Research Foundation (P.O. Box 935, West Newbury, MA 01985; 508/462-1990; e-mail: fraxa@destek.net) or National Fragile X Foundation (1441 York St., Ste. 215, Denver, CO 80206; 800/688-8765, 303/333-4369, fax).

In this column,
David Hirsch, M.D.,
a pediatrician and
member of the
EXCEPTIONAL
PARSIT'S Editorial
Advisory Board,
answers questions
from readers. Dr.

Hersch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch is responding to letters and has not examined the child in question, parents need to review his suggestions with appropriate professionals. Dr. Hirsch Wentions specific products or medications only to illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, (617) 730-8742 (Fax).



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Obtaining regular employment and a driver's license, learning to play the piano and organ, marriage and independent living—these are just a few of the milestones we see achieved in this hopeful video. Order from: Utah Down Syndrome Foundation, Southern Utah Chapter, 1035 E. 100 South, St. George, UT 84770; 800-773-0437; \$15, includes postage. Proceeds benefit the Utah Down Syndrome Foundation.

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The HEATH Resource Center offers brochures and papers about postsecondary education for students with disabilities:

- Getting Ready for College: Advising Students with Learning Disabilities offers information for students and student advisers. The paper discusses disability awareness, transition and assessment, arranging for special administration of college entrance exams and contacting campus disability officials before applying.
- 1995 Financial Aid for Students with Disabilities provides information on scholarships and other resources. The paper gives advice on filling out financial aid forms and computing disability-related expenses, and lists organizations providing scholarships specifically for students with disabilities.
- The Americans with Disabilities Act (ADA): The Law and Its Impact on Postsecondary Education describes the law and the rights of students. When requesting this brochure, ask also for Section 504: The Law and Its Impact on Postsecondary Education.

For free single copies of any of these polications, contact HEATH Resource Center, One Dupont Cir., Ste. 800, Washington, DC 20036; (800) 544-3284 (V/TTY), (202) 939-9320 (V/TTY).

#### **Essay Contest for Children**

The National Association for Medical Equipment Services (NAMES) is conducting "There's No Place Like Home," an essay contest in which children aged 8-13 can point out the benefits of home care using home medical equipment services. To enter the contest, a child should write a letter to Pres. Bill Clinton on the following: "In 100 words or less, explain why you are glad hor e medical equipment services or rehabilitation/assistiv : technology allows you or your relative to be cared for at home rahter than at a hospital. Why do you like it better? If you are writing about a relative, why do you think he or she likes it better?" First place state/ regional winners will receive a \$100 savings bond and compete for the national prize—a \$500 savings bond and two-day all-expenses-paid family trip to Washington, DC. Local and national runners-up will also receive prizes.

Send essays to Deidre Moore, Manager of Communications, NAMES, 625 Slaters Ln., Ste. 200, Alexandria, VA 22314-1171. All entries must be received by July 17, 1995. For more information, call (703) 836-6263.

**Support Groups** 

- The National Spinal Cord Injury Association (NSCIA) has started the free In Touch With Kids (ITWK) program to help children and youth under the age of 18 with *spinal cord injuries* connect with each other. ITWK members receive NSCIA's quarterly newsletter and the *Pen Pal Partners Catalog* with names and addresses of other kids around the world. Contact NSCIA, 545 Concord Ave., Ste. 29, Cambridge, MA 02138; (617) 441-8500, (617) 441-3449 (fax).
- The Biliary Atresia and Liver Transplant Network provides a support network for families of children born with biliary atresia (both pre- and post-liver transplant). For more information, contact Biliary Atresia and Liver Transplant Network, 3835 Richmond Ave., Staten Island, NY 10306; e-mail: OrganTrans@aol.com.

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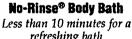




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#### **Directory of Advertisers**

Circle	Advertiser Page	Circle	Advertiser Page
219	A & D PRODUCTS, INC	241	JOHN WILEY & SONS85
253	ACADEMIC SOFTWARE, INC54	140	JUST TWO BIKES, INC108
103	ACCESSABLE ENVIRONMENTS52		KALEIDOSCOPE
	ALLY CAT BICYCLES, INC		KENNEDY KRIEGER88
	AMBUCS RESOURCE CENTER129		KEYSTONE CITY RESIDENCE
	AMERICAN PUBLISHING41	98	KID-KART/KID CARE
205	AMIGO MOBILITY		KIMBERLY-CLARK
220	APPLE COMPUTER		LAUREATE LEARNING
	AQUATIC THERAPY		LUBIDET USA, INC
	ARC/OTSEGO84	1	M.J. MARKELL SHOE CO
62	ASSOC. FOR BIRTH DEFECT CHILDREN37	78	MARTHA LLOYD COMM.SERVICES
	BALL DYNAMICS INT'L INC		MARYLAND INSURANCE GROUP
240	BANCROFT	131	MARYLAND INSURANCE GROUP 16-21
39	BARRIER FREE LIFTS114	93	MED GROUP53
231	BEATRICE M. BRANTMAN, INC	242	MEDICAL JOURNAL RESEARCH 109
10	BERKSHIRE MEADOWS		N.O.R.D.(NAT'L ORGANIZATION
	BETHPHAGE MISSION		OF RARE DISORDERS)
	BETTER BABY PRODUCTS INC	237	NAT'L ASSOC. OF PRIVATE SCHOOLS
	BRAUN CORPORATION	76	FOR EXC. CHILD
	BROWN ENGINEERING CORP	76 21	NEW ENGLAND CTA FOR ACTION44 NEW ENGLAND VILLAGES
	C & V CARING FRIENDS INC		NR LABS, INC
	CARE ELECTRONICS		ORALGIENE
38	CHILD QUEST, INC		OTICON, INC
11	CHILDREN'S SPECIALIZED HOSPITAL98	186	PERMOBIL, INC
146	CHRYSLER CORPORATION	256	PHONIC EAR42
180	CLARKE HEALTHCARE PRODUCTS, INC54	12	PLUM ENTERPRISES
	COLUMBIA MEDICAL	89	RINCIPLE BUSINESS
	CONCEPTS IN CONFIDENCE74	- 40	ENTERPRISES, INC
	CONVAID		PUREFLITE GEAR24
73	CROTCHED MOUNTAIN REHAB73 CROW RIVER INDUSTRIES23	63	Q'STRAINT
74	CUMBERLAND HOSPITAL		REDMAN128
	DANMAR PRODUCTS72	240	REPRISE CORP
	DEVEREUX FOUNDATION40	85	RICON CORPORATION
	DIESTCO MANUFACTURING54	41	RIFTON, INC
254	DISABLED CHILDREN RELIEF FUND64	171	ROCK 'N ROLL CYCLES
141	DON JOHNSTON126	47	ROLEEZ WHEEL SYSTEM108
	E-Z-ON PRODUCTS, INC	238	SEATCASE100
255	EDVANTAGE MEDIA112		SENNHEISER
400	EPILEPSY FOUNDATION OF AMERICA90		SENTIENT SYSTEMS TECHNOLOGYC2
	EQUIPMENT SHOP84	130	SPECIAL DESIGN
31	ESTATE PLANNING	162	ST Coletta of (MA)121
	EVERGREEN CENTER, INC	17	
'00	EXPOCON MANAGEMENT ASSOC., INC111	••	& MEDICAL CENTER39
156	EXPRESS MEDICAL SUPPLY	4	STEWART HOME SCHOOL102
	FLAGHOUSE54	121	TEMASEK TELEPHONE95
135	FORD13	40	TIGER COMMUNICATIONS88
168	FREEDOM DESIGNS46	19	TMI45
	GENERAL MOTORS	20	TMI
1	GOSHEN ENTERPRISES		TMI
235	HANDI-MOVE		TOYS FOR SPECIAL CHILDREN91
1	HAVERICH ORTHO SPORT74	100	TRIAID
14	HDIS	46	TRIAID95
	HEALTH HILL HOSP, FOR CHILDREN8	33	VAIL PRODUCTS
3	HEARTSPRING	102	VANTAGE MINI VANS
77	HMS SCHOOL80	247	VIEWPOINT MANUFACTURING, INC 50
101			VOORHEES PEDIATRIC FACILITY97
1	I-2 KIDS CLOTHES62		WHEELCHAIR GETAWAYS
26	JA PRESTON		WHEELERS
	INNOVATIVE PRODUCTS	91	WILLOW RIVER FARMS
	INTER-MED	72 249	WOODBURY PRODUCTS
14/	JEREMY P.TARCHER	249	#20000n;   11000018
	JESANA82		
	223,474		



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Facility	D. Are you an EDUCATOR? Tyes In No
Address	If Yes, □ Special Ed Teacher □ Regular Ed Teacher □ Admin/Dir are you a: □ Other (please indicate)
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Phone Fax	
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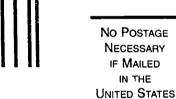
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Maddak, Inc., Pequannock, NJ 07440-1993

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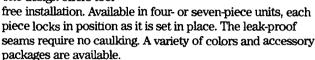
#### **METRO BASIC BUGGY**

The Metro Basic Buggy (Model 3M) is a stroller that provides basic transportation for children ages 5 to 12 or weighing up to 125 pounds. The buggy features a lightweight aluminum-and-flexible-steel folding frame. A sling seat with an integrated trunk stabilizer provides proper seating and positioning. Equipped with toggle brakes for safety.

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Osprey Engineering, Winchester, MA 01890

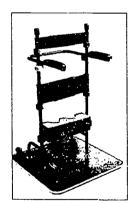
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Tumble Forms, Jackson, MI 49204-0089

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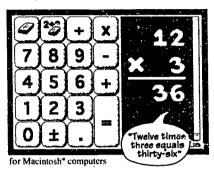
The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT'S "Free Product & Information Card." Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).





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## RESEARCH

## The Special Parents Project A survival guide for new parents

by Bruce Robinson and Lorna Catford

he birth of our two-vear-old daughter, Naomi, inspired the creation of the Special Parents Project. Her condition-an undiagnosed neuromuscular disorder and profound developmental delay-led us to re-examine our professional priorities (Dad is a writer and Mom is a psychotherapist and educator). Now we are pursuing our new dream of providing a caring guide for others who unexpectedly share our abrupt and disorienting journey.

When we were told, "Naomi's not OK." we didn't know where to turn. We knew no one in the special needs community. We didn't have a clue about how to deal with the medical and insurance system, nor did we know any of the resources that might be available to us. We felt painfully alone with our shattered dreams.

We searched libraties and bookstores. We found books about specific diagnoses, but nothing to give us the support we needed right then, when we were dealing with the ir itial grief, panic, immobilization and disbelief.

#### Writing the book we couldn't find

Now, we have set out to write the book that we couldn't find. The first step was the creation of a set of questions for other parents to answer about those difficult first months after a child with a complicated medical situation is born. Our questionnaire addresses subjects such as family and sibling relationships, financial impact of a child's disability and sources of interpersonal and emotional support.

The responses from this survey will be compiled and published in a "survival guide" for new parents, to offer them empathy, support and ideas for making it through the pain and adjustment of the first year. A pilot project has already been completed in association with California State University at Sonoma. We will report on our work

and publish excerpts in future issues of Exceptional Parent. In conBruce Robinson and Lorna Catford are pictured here with daughters Amber, 4, and Naomi, 2.

junction with the book, the Special Parents Project will also establish a support network for parents and work to boost public and legislative awareness of disability issues. In addition to your survey responses, we welcome any referrals or ideas for funding our project.

As we head into the third year of our own special parenthood, we are learning to balance the demands of dual careers, the needs of Naomi and big sister Amber, 4, domestic chores and our effort to extend care and connection to the courageous and overwhelmed souls feeling their way along this unplanned path.

#### Your participation is invited

You are invited to participate in a study of the experiences of parents whose infants are critically ill or have other special needs. Please respond to each question (see next page) in as much detail as you wish. You may answer just those questions that seem most important to you. Please indicate the number of each question to which you are responding.

You can write or type answers on a separate sheet of paper or record your answers on a cassette tape if that is easier than writing or typing. You can also send your responses on a 3.5" Macintosh- or IBM-formatted computer disk (saved as a "text" or ASCII file) or by e-mail to lorna.catford@sonoma.edu.

- · Give specific instances when possible.
- Share tips that might be helpful to
- · Short answers are fine; we'd prefer short answers to not hearing from you at all.
- · Fathers are especially encouraged to respond. **EP**



#### A: BACKGROUND

1. Your name, address, and phone number. (Optional) May we use your real names?

2. Who are the members of your family (names, ages, relation to you)? Which family members have special needs?

#### **B:** DISCOVERY

- 3. How did you first know something was wrong?
- 4. What is your child's diagnosis or disability?
- 5. How were you informed? Who told you? In what setting? Who was there?
- 6. What were your reactions? What did you feel? What did you do? Were you referred to any support services?

#### C: THE EMOTIONAL ROLLER COASTER

- 7. How have your feelings evolved since finding out about your child's disability?
- 8. How have your values, priorities, world view or religious faith been affected?
- 9. What are your greatest fears? How do you deal with them?
- 10. What is the worst thing that has happened? How did you handle it?
- 11. What do you do to take care of yourself?
- 12. What truths or personal strengths have you discovered?

REQUIRE A RESTRAINED ENVIRONMENT

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of child's room

or Medicare

#### D: RELATIONSHIPS

- 13. What has happened to your relationship with your mate? Do you have any advice for other couples?
- 14. How do you meet your other children's needs? How do they and their "special" brother or sister relate?
- 15. In what ways have grandparents, other family members and friends been supportive or problematic?
- 16. If you are a single parent, what are the needs and issues that are specific to the absence of a partner?
- 17. What opportunities have you found for networking with other special parents? What has been most valuable or useful about those contacts?

#### E: FACING THE WORLD

- 18. Describe the daily routine with your child. What's hard? What's become easier? What helps?
- 19. How do you get doctors, insurance companies, agencies and medical bureaucrats to take your concerns seriously?
- 20. How has your child's condition affected your financial situation? Your work? How are you coping?
- 21. Recall instances in which you had to handle strangers' reactions to your child. What did you do?

#### F: HEAVY ISSUES

- 22. Have you at any time had to deal with your own disability or serious illness while caring for your child? How did you manage?
- 23. If you have lost your child, what was that like for you? How did you cope?
- 24. Have you considered placing your child in out-of-home care? What has that been like for you?

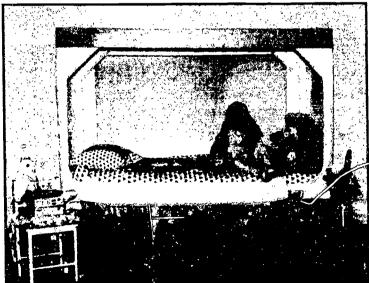
#### G: FINAL THOUGHTS

- 25. What books, publications or groups have been most helpful for you?
- 26. What ideas can you share for dealing with specific issues raised in earlier questions?
- 27. What healing advice can you give other parents regarding picking up the pieces of shattered dreams?
- 28. Do we have your permission to use your name and the other names you mention in any published materials based on this survey?
- 29. Would you like to communicate with other parents as part of a support network related to this project?

If you would like to send us copies of any of your art, poetry or journal entries relating to your experiences with your special child, we would love to see them. Send them along with your responses to the questions to: Bruce Robinson and Loma Catford Ph.D., The Special Parents Project, 5954 Van Keppel Rd., Forestville, CA 95436, (707) 887-2154. Our Internet address is Ioma.catford@sonoma.edu.

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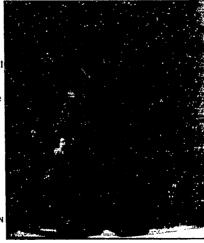
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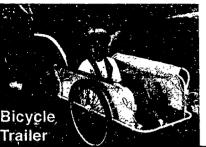
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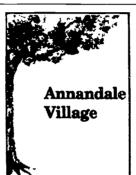
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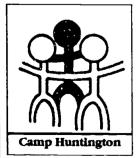


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fanatic, I find myself living

you what happened in the

with a daughter who can tell

first game of the NFL playoffs

three years ago. Many people

are surprised to learn that

Serena enjoys "watching"

sports; they are even more

surprised that she partici-

eral public assumes blind

people cannot be involved.

pates. Sports is just another

area of life in which the gen-

But we began learning a

valuable lesson when Serena

was just a baby-that there's

almost always a way to get a

whether a sports game or the

game of life. We have made it

blind kid into the game,

lthough I never thought

## CHILDREN'S PAGE

## PLAY BALL!

by Serena Cucco

ack when I was in second grade, I began going to my dad's coed softball games. It was there that I got interested in baseball. Mom and the other players gave me the play-by-play so I could follow the game. The players had high spirits. Coach would bang his glove on the bench and yell, "Defense! Defense! Let's get those outs!" The men would yell and holler, especially if there were controversial calls. I even heard some bad language being uttered from their mouths! Baseball seemed like an exciting sport.

One day, Daddy called Mom from work and said, "Get your sneakers on. We need one more woman to play tonight or else we have to forfeit."

Mom didn't really want to play because she had no experience, but she didn't want the team to have to forfeit, so she got her sneakers on and went to the field. Monimy wasn't exactly the best player the ball club had ever seen, but her being there allowed the team to

play for the rest of the season.

By now, three-quarters of my family were playing baseball. My mom and dad were playing once a week and my brother was playing T-ball on Saturday mornings. There was only one quarter left not playing-me! I decided I wanted to play T-ball too. I got ready by swinging my Thunder Bat 25 times a day.

The next season, I joined my town's T-ball league. My brother and I were on the same team. I got a lot of good base hits. I ran the bases and took the field with a coach.

I started to listen to professional baseball on the radio. My favorite team was—and still is—the Mets. (Go Mets!) Listening to the games helped me decide I want to become a sports announcer when I grow up. A sportswriter friend of our family arranged for me to meet color commentator

Don Wardlow at work as the New Britain Red Sox took on the Trenton Thunder. It just so happens that Don Wardlow is blind and so am I! I spent an actionpacked day with Don, his partner Jim Lucas and Gizmo the Wonder Dog, Don's guide dog.

Nowadays, my sport is kickball. I play every day at recess with the fifth and sixth graders. We adapt the game by having somebody stop the ball with her foot in front of my foot. Then I kick. I run the bases and take the field with a teammate. The teachers say "nice try" to all the players, no matter what team they are on. I'm more competitive than that—I only root for my own team!

Next year, I plan to play girl's softball in the town league. I'm looking forward to a great season. **EP** 

Serena Cucco is 11 years old. She lives in Madison, New Jersey with her parents, Bill and Carol, and her younger brother, John, 8. Serena is a fourthgrader at Kings Road School in Madison, where she especially enjoys writing workshop, science, spelling, football and recess.



While visiting blind sports commentator Don Wardlow in July, Serena met and interviewed Patrick Lennon of the New Britain Red Sox, Serena's interview with Lennon was played on the pregame show and published in USA Today Baseball Weekly.

Batter up! Serena suited up last April for a game in the Madison Little League.



a point to get to know lots of blind adults, many of whom hold jobs most people would assume are impossible for a blind person to do. We're determined to keep all the doors open for Screna; we

thank these adults and the National Federation of the Blind for inspiring us to do just that.

---Carol Castellan

the Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: Children's Page, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.





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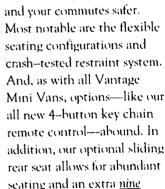
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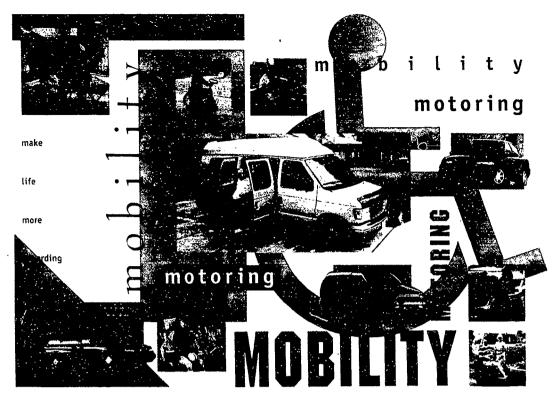
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JULY 1995 VOL. 25, ISSUE 7



PAGE 24

^4

# Your CHILD OR YOUNG ADULT WITH A DISABILITY

Since 1971

Cover: Deanna Simon (left), 20, a student at The Connecticut Institute for the Blind/Oak Hill School, spends some time with her friend Justina Kleczkowski, 12, a student at Slade Middle School, where Deanna's classroom is located.

At Oak Hill, community integration is part of everyday life. It begins at home, where students live in small residences located in family neighborhoods. Opportunities for friendship and peer interaction continue at school, because Oak Hill's educational programs are typically located in public school settings and provide numerous opportunities for shared activities. Photo: Roger Maynard, Applied Photography, Glastonbury, Connecticut.

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#### FRIENDSHIP

One mom's cure for the "summertime boredom blues."	24
Readers Talk About: Friendship	28
RESCUE 9-1-1 by Jolie Kanat	28
JUST FRIENDS by Jean Sigler	29
Appreciating Differences by Teresa R. Callahan	29
SPECIAL FRIENDSHIPS by Lynne Tamor	30

#### COMMUNITY PARTICIPATION

COMMONTALITATION	
Building Community Resources by Serena Umstead, Kimberly Boyd & Carl Dunst  Enabling inclusion in community activities.	36
A Championship Season by Rose Gilbert	39
<b>Respite Care and the Religious Community</b> by Bill Van Dyken	41
Integrated Neighborhood Play Groups by Trudy Marsh Grable	44

#### **COMMUNICATION**

Why Parents and Children with Disabilities Should Have the Right

to Use Facilitated Communication by Douglas Biklen	40
Departments	
Editor's Desk	2
Letters	4
Search & Respond	8
Role Models: Tom Hershey	16
Familiar Faces	31
Fathers' Voices: GROCERY BAGGAGE by Timothy Perry	32
Media: Taking Charge	47
Youth Connections	5
Health Insurance Troubleshooter: Self-Funded Insurance Plans	55
Ask the Doctor: The Ketogenic Diet	56
Directory of Advertisers	59
New Products	6
What's Happening	62
Exceptional Pare nt Library	6
Children's Page 'Restret Runs's 'by Kristen Gain	



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## EDITOR'S DESK

#### **Community inclusion begins with friendship**

As they venture out into neighborhoods and communities—participating in new activities, trying to make friends—children and young adults with disabilities,



STANLEY D. KLEIN, PH.D.

and their parents, learn a lot about taking risks. There are risks when we try to be independent; there are also risks when we reach out to ask members of the community for assistance.

As children develop, it is natural that they want to test their abilities and limitations by taking on new challenges. Parents—often recalling their own childhood struggles with similar issues—want to encourage their children, but at the same time, find themselves constantly weighing the potential benefits of a child's participation in any new activity against the risks of pain, injury or embarrassment. Parents seek the perfect balance between protection and overprotection.

In recent years, increased attention has been paid to the development of social skills. Adults have come to appreciate the importance of friendships. Academic or mobility skills are important, but loving relationships contribute even more to a fulfilling life. And participating in a community, with its interconnected network of relationships, is another important part of living.

In this issue, we are pleased to provide wonderful examples of the ways parents and professionals are creating opportunities for children and young adults with disabilities to make friendships and become full participants in their communities. The social commentators who bemoan the disappearance of community life would do well to read the stories in this issue. From Maglia, California, to Rock Valley, Iowa, to Pottstown, Pennsylvania and beyond, these stories demonstrate that communities can respond to the needs of their members in ways that are supportive and meaningful for all. They also show that the inclusion of young people with disabilities and their families enhances the life of the community as a whole—after all, what is "community" if not a place where each person benefits from and depends on the participation and contributions of every other?

#### The risks of controversy

When we published material on facilitated communication (FC) in our May issue, we knew we risked upsetting some dedicated readers, both parents and professionals. At the same time, we felt we had a responsibility to present thoughtful perspectives on this topic.

It is clear that there are different points of view—as evidenced by both the strong letters we received in response to the May issue and Dr. Biklen's article in this issue. We are committed to providing a forum for caring parents and professionals. That is why Dr. Biklen's article appears in this issue—despite the advice of some people who recommended that we not publish it.

For more than 40 years, I have worked with people with disabilities, their families and professionals. In that time, I have had the honor of meeting many wonderful human beings. Virtually all were caring, compassionate people, deeply dedicated to children and families. However, we have not always agreed with each other on all matters. And there are times when, in the heat of discussion, it can be difficult to disagree without becoming disagreeable.

I am saddened that some readers perceive our reporting on FC as pitting parents against professionals. *Exceptional Parent* has always been dedicated to respecting and supporting the expertise of parents, and promoting the need for parents and professionals to collaborate respectfully. We will continue to publish information and opinions on FC and other controversial subjects, and we invite your participation.

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## LETTERS

## Sharing Our Children With the World

The April 1995 issue of *Exceptional Parent* included an incredible series of articles describing family vacations enjoyed by families who have children with disabilities. These stories were uplifting and inspiring. I'm sure they will inspire many—including my wife and I—to consider trips hitherto deemed impossible.

After reading all these vacation stories. I came to the last one, entitled "Sharing The World With Our Children." Given the mood and message of all these first-hand accounts, I'd almost suggest changing that last title to "Sharing Our Children With The World." That title would better express another theme and accomplishment of all these stories—the effect on all the people who meet these families on their trips must be very positive and enlightening. Thanks for a great issue!

B.R., New York

#### **Full Circle**

I remember the first time I ever saw a copy of Exceptional Parent. I was just getting used to the idea of having a baby with Down syndrome, but very worried about what life was going to be like-for him and for me. And there, in the library, on the cover of your magazine was the picture of a smiling child with Down syndrome. At first, I couldn't really look at the child on the cover, I just took quick glances. Every week, I went to the library to find books about mental retardation and child development. Each time, I looked just a little longer at the cover of the magazine. Finally, I took a big step-I opened it!

It took several more months before I actually brought a copy of *Exceptional Parent* home and read it. Now, five years later, there is my son smiling at other new parents from page 26 of the May issue. (I'm starting to cry as I type this.)

Anyway, what I'm trying to say is

thank you, thank you, thank you for your work and dedication to serving parents!

Barbara Mitchell West Liberty, Ohio

Editon's Note: Barbara Mitchell's story about her son, "Making Turntaking Fun," appeared within James McDonald's article, "Turn-taking: A Giant Step To Communicating" (May 1995).

#### **Facilitated Communication**

As the parent of an exceptional young man who uses facilitated communication (FC), I was dismayed and disappointed at your supposedly informational article on the topic ("Facilitated Communication: What Parents Should Know," May 1995). Your obvious bias was so blatant I had difficulty finishing the article.

Just because you and other "professionals" don't understand and can't accept a non-traditional method of communication doesn't give you the

continued on page 6

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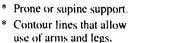
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#### LETTERS

continued from page 4

right to condemn the process. The "reading and research" you claim to have done focused only on the negative aspects of FC presented by people with another agenda.

I don't claim FC is a miracle or a cure. But it is a means by which nonverbal individuals can express their thoughts—not just canned phrases from a language board. One of the first things my son "expressed" after beginning FC was to throw his language board.

That article only focused on the negative situations that can occur when people abuse an FC user. Abuse allegations are the exception rather than the rule, but they get much more attention than all the FC successes. What about the documented use of FC by people who now type independently? Why did you ignore the research done by people like Doug Biklen?

Your magazine has done a grave injustice to FC and to those people who, like our son, can now express their thoughts and feelings. As an apology to their parents, you must publish the research results that show the positive aspects of FC.

Ann O. Reeves Watsontown, Pennsylvania

■ For "exceptional" parents, there is nothing more burdensome than false hope, and few things more valuable than reasonable expectations. Expectations establish the standard upon which successes and failures are measured. Successes validate our choices and our parenting skills, allowing us to experience pride and happiness in the accomplishments of our child with disabilities. In turn, we are empowered to meet our own needs, and the needs of our spouses and children.

The May 1995 issue of *Exceptional Parent* was most exceptional. Both editor and publisher should be commended for their courage and professionalism. Truth and honesty are the greatest gifts a parent can be given.

G. Emerson Dickman, III Maywood, New Jersey

■ With the publication of the article on facilitated communication, you have ceased to be a source of valuable, unbiased information for parents. Instead, you have joined the ranks of doctors who believe that people with developmental disabilities can't possibly have any intellectual ability, pedagogical teachers who refuse to relinquish control, and the stifling system of so-called "consumer-oriented" service providers.

After 27 years of silence, my daughter, Leslie, using an augmentative communication device with the therapeutic technique of FC, can tell me when she has a toothache and where and how she wants to celebrate her birthday. She tells us that she taught herself to read by age six and explains about the distortions in her visual



Circle #173

perception. She can also tell her threeyear-old niece, Sarah, that she loves her—with Sarah doing the facilitating. Sarah is a bright little girl but she doesn't know how to spell. Sarah's ability to facilitate with Leslie is one of many confirmations I have had that it is Leslie doing all the talking.

These are Leslie's words—"We are smart. We are waiting so long. We are getting tired. The system prevents the person from getting the proper equipment. The system is the reason we are not productive. The system is doing nothing to help."

Inform yourself, *Exceptional Parent*, and look to the positive research that is available.

Barbara Lockerman Washington, Pennsylvania

■ Authors Karen Levine and Robert Wharton encourage parents to have FC eliminated from a child's school program when they suspect a facilitator may be influencing communication. But rather than presenting FC as something that either works or doesn't, it needs to be understood as a process that requires ongoing problem-solving and the establishment of safeguards.

Even if parents discover that communication has been influenced, there are potential solutions to that problem that should be tried before they completely eliminate what may be the most valuable augmentative communication system for their child. In addition, parents should be encouraged to have FC included in their child's IEP when it is the child's primary means of communication.

Betsy Knafo Brooklyn, New York

■ Thank you for your factual, objective article on FC. As a registered nurse and case manager working in the developmental disabilities field, I will not ignore research. It seems that most professionals feel as I do, and FC is now used primarily for personal communication between parent and child. This is probably okay. Mothers and fathers

have always "verbalized" their infants' cries—correctly interpreting "you want to be changed" or "you are hungry."

Still, putting exact words in the mouths of others is a scary concept. I challenge all FC believers: do your own investigation—let a machine or other device steady your child's hand. What are the results? The fact that FC often "works" with only one facilitator should be a red flag.

Just last week, I attended a conference where a well-known speaker expounded on the virtues of FC. When the audience asked difficult questions, the answer was always the same—"Just ask the FC user what he or she wants."

Parents who use FC with their children need to ask thenselves this question: "When I am no longer around to 'speak' for my child, who will?" Will their daughter someday "request" a hysterectomy because she has stated through FC, "My periods are too painful?" Tough situations like this happen all the time with nonverbal adults, many of whom are cared for by someone other than their parents. As an advocate, I always ask, "Who really wants this, and why?"

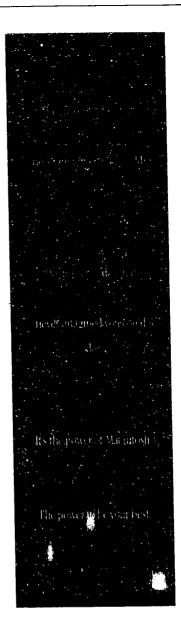
Parents and professionals must work together to protect all people who cannot speak for themselves. FC has already caused devastation across the nation. Blindly perpetuating a false theory, no matter how wonderful it seems now, may come back to haunt—no, to harm—the sons and daughters we so dearly love.

Gail Wolf, RN/CM Roseburg, Oregon

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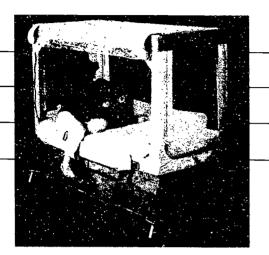


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## SEARCH

#### **Self-Stimulation and Smearing**

My 10-year-old daughter suffered brain damage at one day of age as a result of hypoglycemia. Aimee has severe mental retardation. She is nonverbal, wears diapers and has an uncontrollable seizure disorder.

At age three, Aimee started touching and rubbing her genital area. I brought this to the attention of her occupational therapist, pediatrician and neurologist. They all said "masturbation" was age-appropriate and recommended that I ignore it.

Ignore it I did. For several years it was not a problem, then Aimee found out how to get her hands in her pants. Eventually, she began to stimulate herself enough to cause a bowel movement. She would then smear herself from head to toe. Her teacher called this "body painting." For a while, I solved this problem by dressing her in one-piece outfits, even making her clothes myself as she grew and it became difficult to find one-piece outfits in her size.

Now, however, Aimee has figured out how to slip her hand up her pants leg to get to her diaper. She has even figured out how to dig her fingers in at the crotch on the outside of her pants. Needless to say, I've had to wash many clothes, and give many baths.

Aimee does not realize that this behavior is inappropriate. I have no way to let her know this behavior is unacceptable. I now hesitate to get babysitters because if Aimee does a whopper of a "body painting" job, they won't come back.

Aimee will soon start summer camp, and I'm afraid there are going to be a lot of problems, especially when the kids go swimming. Aimee has not started menstruating yet and I can't imagine what might happen when she has her period.

Does anyone have any ideas for breaking Aimee of the habit of masturbating and "body painting," or ideas for keeping her hands out of her pants? Aimee's previous occupational therapist, Debbie, has remained a good friend. Debbie is willing to help me create something that would give us a better quality of life. I'm at the end of my rope now and desperately need help.

K.D., Pennsylvania

#### **Residential Care**

My three-year-old son has been diagnosed with infantile spasms, microcephally, mental retardation and autism. He lived at home with me until a few months ago. My son's disorders caused extreme behavioral problems; he would scream for ten hours a day. I was constantly exhausted and felt I could not care for him any longer. Finally, I placed him in a residential care facility. I am so heartbroken and depressed. I need to talk to other parents who have placed their child.

K.S., Ohio

continued on page11

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continued from page 8

#### Water Bed?

My one-year-old daughter has spastic quadriplegic cerebral palsy. Because of her limited movement, I am concerned for her comfort and often go into her room during the night to turn her. Although she sleeps on a high-quality mattress with a lamb's wool cover, there is always a dent in the mattress in the spot she has been sleeping.

I am wondering if a water bed or any other type of special mattress might be more appropriate and comfortable for her. I would appreciate advice from parents who have had experience with different types of mattresses.

D.S., Massachusetts

#### Chromosome 18p-

My 16-year-old daughter was born with a partial deletion of the short arm of chromosome 18 (18p-). As an infant, she had hypotonia (low muscle tone) and developmental delays. At the age of 12, she developed muscle spasms and tremors. Doctors tell me that they know of no other person with 18pwho has developed these symptoms. I would like to hear from anyone whose child has similar problems.

C.W., British Columbia, Canada

EDITOR'S NOTE: The Chromosome 18 Registry and Research Society (6302 Fox Head, San Antonio, TX 78247; 210/657-4968) can put you in touch with other parents of children with 18p-. Their registry currently lists 51 children with this condition.

#### **Peters Anomaly** and Dental Problems

We are the parents of a happy, twoyear-old named Benjamin, who has Peters anomaly (a condition where there is adhesion of the cornea to the iris). As a result, he has congenital glaucoma and vision of approximately 20/600. In addition, he has hypotonia (low muscle tone) and developmental delays.

Despite his disabilities, Benjamin

gets around very well. He crawls everywhere and is starting to stand without support.

Now, we have a new concern. Benjamin has only nine teeth, and half of them have come in fused. We have taken him to a pediatric dentist, who has answered some of our questions, but we would also like to correspond with parents who have a child with this type of dental condition, or any parents of children with Peters anomaly.

> R.L. & C.L., Michigan continued on page 12

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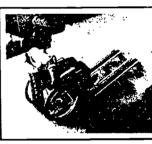
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The joy of anticipation was all over his face...Troy's dad was taking the training wheels off his bike. His dad helped him get started...then, he let go... and Troy was doing it, he was riding all by himself!

Troy's father knew that sometimes the hand that helps most is the hand that lets go. So did the parents of Victor, a young boy with multiple disabilities.

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Now, five years later, Victor attends public high school classes for a couple hours, then goes to work at a restaurant on the campus of a local state university. He has learned to tolerate walking in hallways that have over 1,000 students on their way to class! Currently, staff are working on other needs Victor has to ease his transition from Heartspring to his home community.

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#### SEARC

continued from page 11

## Developmental Apraxia of Speech

My five-year-old son was diagnosed with developmental apraxia of speech (DAS) several years ago. I have been unsuccessful in my search for information on this subject. Are any universities or clinics doing research on this condition? I would like to hear from any therapists or educators who have worked with children who have apraxia.

Finally, I would appreciate hearing from parents of children with DAS. Is there a DAS support group out there somewhere? I want to sign up!

S.A., Arkansas

EDITOR'S NOTE: The National Organization for Apraxia and Dyspraxia (7675 Charter Oak Dr., Pennsecola, FL 32154; 904/478-4895, voice; 904/494-1444, TTY) can provide information about DAS. They can also put you in touch with other families dealing with this condition.

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

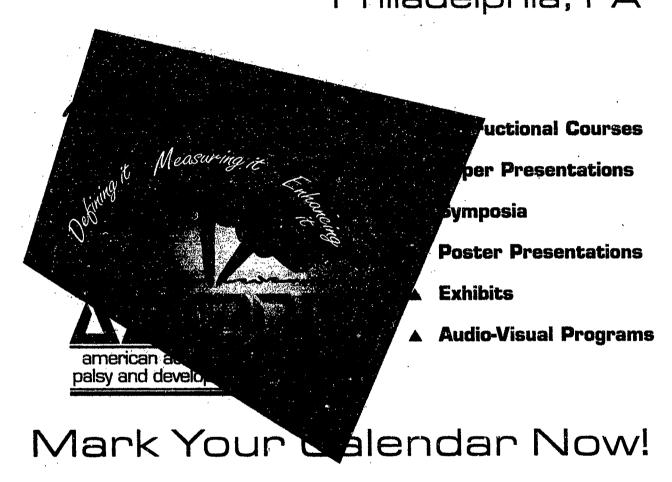
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Write or fax: Search or Respond, Exceptional Parent 209 Harvard Street, Suite 303, Brookline, MA 02146-5005 Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in Exceptional Parent's 1995 Resource Guide (January 1995).

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## RESPOND

#### **Dealing with Seizures**

D.R., (May 1995) has a son. Christopher, who is almost three years old. He has cerebral dygenesis, meaning that roughly half his brain is gone. He has developmental delays, hypotonia, slightly clubbed feet, farsightedness and a seizure disorder that is mostly controlled by Dilantin. But when Christopher does have a seizure, he stops breathing. D.R. wanted to know how other parents deal with seizures, especially how they sleep at night.

My family and I could write a book about seizures. Our son, Timmy, is four years old now. When he was 23 months old, we were told he had severe mental retardation. Boy, did those words change our world! But, later that month, we found out what it was really like to have the walls come tumbling down; that was the day Timmy had his first of many seizures.

We found Timmy in a pool of vomit in his crib. At first, we thought he had just spit up and gone back to sleep until my mother-in-law, who is a nurse, scooped him up and started doing CPR. Then I realized my son was not breathing, obviously had not been breathing, and could very well die.

Since we lived in a small rural town, the local hospital promptly flew Timmy to a major medical center. We had to drive for 45 long minutes, not knowing if he would be alive when we arrived. He was started on Dilantin and was fine for just two days when he had another seizure-and this one lasted for three hours!

Since then, Timmy has had more seizures than I can count. With every one, he has stopped breathing-just like your son.

Last November he had the scariest seizure of all, because we didn't

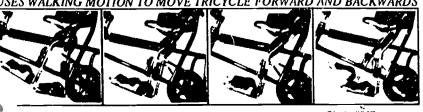
know it had happened. Again, we found him in a pool of vomit. His lips, fingers and toes were blue, and he was scarcely breathing. To top it all off, our wonderful pediatrician was out of town. All doctors deserve a vacation, but he chose to have his when Timmy was crashing! Thank goodness we were able to reach Timmy's neurologist who promptly met us at the emergency room. By that point, Timmy's vascular system had shut down; they had to stick him 27 times to start an IV. While Timmy was in the hospital, his neurologist told us about a new seizure medication, Neurontin, that he thought would help Timmy. Timmy started on Neurontin the day that he was discharged from the hospital and has not had one seizure since-not one.

We do know what your life is like! After Timmy's seizure in November, we felt very guilty that we hadn't

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checked on him sooner and caught the seizure earlier. We know what it's like to go without sleep. We are up a lot at night just to check on Timmy; we can't sleep at all if we don't know he is OK.

I would suggest that you try to find a back-up system for yourselves. It has taken us a long time to be able to trust anyone but ourselves with Timmy, but we can't let ourselves go crazy worrying; sometimes, we just need a break.

Check into your local resources, and see if you can obtain a list of respite care providers. If respite care is not available, you might try placing an ad in the newspaper for an occasional caregiver who is trained and certified in CPR. Or, you might try calling the special education department of a nearby college. That's how we found our babysitter, a terrific young woman who is a speech/language pathology major at the local university. She babysits for us on weekends and occasionally during the week.

I'm not going to lie to you—you probably won't ever sleep a full night again as long as Christopher has seizures. But, with help, you just might be able to keep your sanity.

You are not alone! It is nice for me, too, to be in touch with other parents who are going through the same things. My mother always says God doesn't give us any more than we can handle. Sometimes, I believe her: sometimes, I don't.

E.F., Georgia

#### Stressful Car Rides

C.R. (May 1995) has a 26-month-old son, Austin, who does not have a specific diagnosis, but has been labeled "centrally hypotonic" (having low muscle tone). Austin becomes very upset while riding in a car seat. His parents have tried different car seats and different seats within the car, however, Austin continues to become upset when they put him in the car—crying, screaming and holding his breath until he passes out. C.R. was looking for ideas for making car rides less upsetting for Austin and less stressful for his siblings.

Our wonderful 16-month-old daughter, Sophie, has a peripheral sensory neuropathy and has been centrally hypotonic from birth. Sophie hasn't gotten upset in her car seat lately, but in the past, I found that sunlight and rapid light changes (like those experienced while riding down a tree-lined street on a sunny day) seemed to irritate her. Street lights at night also bother her. We try to keep sunglasses on her and shades around her seat; throwing a light-weight blanket over her car seat actually works best. Though doctors say Sophie's eyes are normal, we feel her system is slow to process and react to changes in light. She also seems to dislike certain noises, like crowds clapping and the noise the car makes on windy days.

We'd love to correspond with you and "compare notes." J.P., Illinois *New from **kid-kart**..!





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## Role Models

## **Tom Hershey**

"My family was a team."

Tom Hershey, 32, is director of operations/associate producer at Sony Pictures Imageworks in Culver City, California. He was born with a still-undiagnosed disability that affects his stature and mobility, and that triggered a kidney disorder at birth.

The following was adapted from a recent interview between Hershey and EXCEPTIONAL PARENT editorial intern Jennifer Koerber:

y family has always been a team that has worked together to make me self-sufficient. I think their reaction to my disability was a decision not to concentrate on the disability, but on the child. This attitude defined the way they dealt with it, and with me, over the course of my life.

#### A homegrown approach

Shortly after birth, I developed a life-threatening kidney infection that required four operations before I was four years old and led to the loss of one kidney. During those years, my health was very touch-and-go. As a result, my disability as a whole was considered a lower priority than its most life-threatening symptom. After my kidney was removed, I started eating better and gaining weight. My parents were then able to begin to think about my other problems. In a way, the immediate danger of the kidney disorder made the disability itself much more manageable.



After two years in Hawaii, Tom's family returned to the mainland when he was seven.

At the time I was born, there was a great deal of interest in genetics and chromosomal disorders. I was first evaluated at the Naval Hospital at Bethesda, Maryland. The doctors looked at my malformed left arm and leg and said, "Yes, this is a very interesting chromosomal disorder. We'd like to run some tests." They tested my chromosomes and said they'd found several anomalies.

When I was five, my father was transferred to Hawaii. A team of doc-

tors at the army hospital decided to do their own chromosomal studies. Their tests came back normal. The doctors back east had either made a mistake or were only seeing what they wanted to see. My parents began to lose



Tom, 12 months, enjoys a tender moment with Mom. At this point, Tom's parents weren't really thinking about his other disabilities. His life-threatening kidney disorder overshadowed all other concerns.

confidence in the medical profession.

My parents did stick with the "experts" a bit longer. Unfortunately, the physical therapy program at the military hospital wasn't geared toward children, or other people like me. It was the first stop for Vietnam veterans with disabilities before they returned to the mainland; so the PT regimen focused on strengthening other parts of the body to replace missing or damaged parts, rather than trying to improve the muscular system as a whole.

The hospital was an enormous facility. My mom had to push me in my wheelchair down miles of corridors. Her solution? She brought my tricycle from home and let me ride it from the parking lot to the therapy room. Slowly she realized that by using the tricycle and another little car that I pumped with my arms, I was building up more muscular strength than I was in my therapy sessions.

My mom resolved to find alternate ways to help me build up my strength. This time, the solution was a little closer to home—the military officers' club swimming pool. We had befriended the pool's lifeguard, Ed Rother, a retired Army football coach. My mother approached Ed, and asked him if he would consider developing a swimming program for me. He agreed.

This occurred during one of my father's tours in Vietnam. At the time he left, I didn't have the muscle strength to lift my head out of the water. Ed began by rigging up a snorkel for me so I could breathe. I swam every day, and rode my tricycle and the little car around the neighborhood, too. By the time my father got home, I was swimming a quarter of a mile a day and diving into more than 10 feet of water to find a golf ball. All this in about six months! My father was amazed at the change this homegrown therapy had made in me.

#### Part of the fabric

The next watershed in my life came after we moved from Hawaii to Vero Beach, Florida. At that time, I had two

continued on page 18



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At age 10, Tom was an enthusiastic Boy Scout.

#### Role Models

continued from page 16 operations to lengthen the muscles in my legs and stabilize my feet. I did some basic recovery therapies after these operations, but I also kept swimming. By this point, I had enough strength to use canes and a walker at home: I only used my wheelchair at school.

A more important change came through my enrollment at St. Edward's School, a private school in Vero Beach. Headmaster Peter Benedict was willing and eager to help a kid who had some physical disabilities and mobility problems, but who had tested very highly in placement exams.

My parents felt able to shift

their focus from my physical needs to my academic and social skills. My mother loves to tell the story of a day when she came to pick me up from school. She saw somebody pushing a wheelchair with a child in it through the trees near the playground. With all the kids running around and having a great time, it took a moment for her to realize that it wasn't me in the chair. I was hiding behind a log, fighting my part of a mock battle from behind the lines. It was at this point that she realized I was going to be integrated into the fabric of these children's lives.

Academically, my adjustment was a little more complex. My first teacher at St. Edward's was an old-school type who immediately laid down the law with my mother-"He may have gotten special treatment elsewhere, but not in this class!" My mother got ready for a fight, but that teacher had my best interests in mind. The teacher knew instinctively that she had to let me flounder for a little bit so I would learn how to pull myself up.

#### A pragmatic attitude

My parents always wanted to make sure that my physical, intellectual and social development were happening together; they hoped to avoid a focus on one at the cost of the others. This pragmatic attitude ruled all aspects of their lives. My parents didn't dwell on my disability, nor the effect it had on our lives. My dad had his job to do with the Navy; my mom had her job to do with me. They were both motivated by the fact that they believed in what they were doing.

If my parents had so-called "typical" feelings like guilt or continued on page 20

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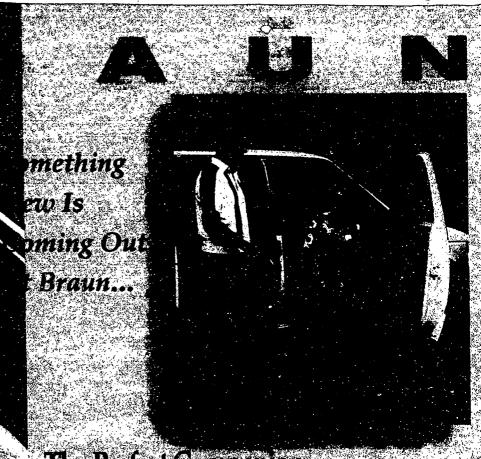


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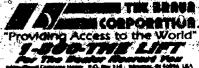
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anger, they were kept from me. Like many military families, we-my parents, my sister and I-were a team. Moving from base to base in my early years taught us independence from standard social services; we relied on other members of the family for support. For better or worse, military life isolated our family from many outside influences.

#### Necessity and invention

I have always loved movies, so it was no surprise that they have become my career. At the Massachusetts Institute of

Technology (MIT), I majored in management with a minor in creative writing. My work in the MIT media lab and courses in entertainment marketing fed my love of film and led me to the MBA program at UCLA, where I concentrated in entertainment management. From there, it was a short hop to Hollywood, and here I've stayed.

While attending both MIT and UCLA, I was a volunteer peer counselor for students with disabilities. I got involved because I had to sit down with the person in charge of disability services and create a plan for getting around the campus. In the disability services office, I often saw college and high school students who were touring the university and



Tom enjoyed a 1994 vacation in the mountains-even though he neglected to pack sufficiently warm clothing!

trying to find out more about disability services. Most seemed very unsure about leaving the security of home. So I offered to speak with any students who wanted to talk to somebody who was out in the world and surviving. That one little offer of help allowed me to talk to a lot of students who came through the university.

#### Upward swing

My life has been on an upward swing since birth. Most of the time, I don't really think about my disability. The only time I'm faced with it is in a new situation; then

I take 15 minutes, figure out how I'm going to do something and then go from there. My disability has always been a part of my life, and it gets more attention from other people than it does from me.

My parents taught me not to be afraid of the unknown and to be inventive about creating ways to be self-sufficient. I'm a little wary of over-reliance on systems that are in place, because I think that may dull the edge of the inventiveness and creativity that you can bring out in children with disabilities. Being able to figure out when any given form of assistance works and when it's not the best alternative may be the most important skill they ever learn. **EP** 

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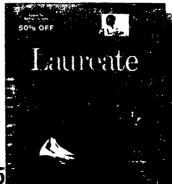
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child:









On "opening day" of the Friendship Club, children proudly wear their newly-created membership badges. Surrounding Erin are (from left) Kaylin and Ryan Gain, Harmony Baker and Kristen Gain.

the lawn in front of our triplex, I'd spread out a large blanket and some of Erin's most stimulating toys. Then, with two-year-old Erin in my lap, I'd spill a large bag of M&M's out in front of us. As I caught the kids glancing in our direction, I'd call out, "Hi, what's your name? This is Erin. Would you like some M&M's? Ask your mom if it's OK."

With a handful of kids sitting on our blanket, I seized the opportunity to teach them about cerebral palsy and blindness. They came to understand that nonverbal doesn't mean dumb; the girls even asked me to help them make gastrostomy tubes for their dolls because, "just like Erin," they couldn't "swallow good."

Soon the neighborhood children were asking if they could come inside to play. Erin's therapy equipment—large balls, colorful wedges and tumbling mats—looked like a lot more

Nick Brown (right) and Erin enjoyed feeding the animals during a trip to a petting zoo.



fun than the toys at their homes. I always kept snacks in the cupboards, too, even though Erin couldn't eat them. And-I admit it-I tried to create some envy when I bought a hamster for Erin's third birthday. "Rodie" worked; she drew the kids over for frequent visits.

'm embarrassed to

admit it, but from

L I've used briberv in

her earliest days

friendships for my

daughter, Erin. I can

still picture my first

hood kids played on

attempts-as neighbor-

Wanting Erin to enjoy life from a kid's perspective, I often asked my neighbors if



## Erin's Friendship Club

by Donna Tatro

I could take their kids on a walk, to the library, to the park or to the zoo. Outings were more exciting for Erin when she could hear and feel the excitement of other children.

Later, we found ourselves across the continent living in an apartment complex full of senior citizens and no other children. I spent time at Erin's preschool and got to know the other children and their parents. Again, I went out of my way to invite her classmates to afternoon or weekend outings with Erin and myself. I would always scan the newspaper to keep abreast of special events for children. And even though Erin is fed solely through a g-tube, every outing included a stop at an ich cream shop or McDonald's to treat her friends. As you might imagine, Erin soon became very popular.



"Bubbly Day" was gleefully celebrated by (from left) Danyel Stoltey, Harmony Baker, Erin, Jenny Nunez, Amanda Jones and Lyndsay Nunez.

#### Filling the summer calendar

The school year had been filled with friends and activities. But as Erin's kindergarten year came to a close, I feared a lonely summer. Though she attended the local school, ours was a mountainous community where most children rode the bus. There were no children Erin's age living nearby. I knew that most of Erin's friends would not be allowed to call and ask if they could come over, most of their parents saw our life as overwhelming, and they didn't want their children to impose. "How does make people understand that I want them



With a little help from my friends: Harmony Baker (left) and Brandy Surplus help Erin with an art activity.

to contact us?" I wondered. That's when I got the idea for "Erin's Friendship Club."

I began by filling up calendar squares with enough activities to occupy every summer week. Ryan, the fifth grade boy who had been Erin's "big buddy" in kindergarten and her helper in Challenger Little League, accepted my offer to be the club president.

I sent the calendar to dozens of Erin's friends from her kindergarten and Sunday school classes and her Daisy Girl Scout troop. In my accompanying letter to their parents, I discussed Erin's disabilities and explained what their kids would encounter at our house—positioning equipment, therapeutic "toys" and various types of medical equipment. I told families that we had invited other children with disabilities to join the "club," and stressed that it was our philosophy that diversity and uniqueness need to be celebrated.

With only a few exceptions, nearly every day was booked. Activities included "camping day" (we opened up the camper and called the wading pool our lake), "bubbly day" (we got out bubble wands and filled the wading pools with bubble bath), "hairy day" (we made our own barrettes and pony tail bands) and "square eyes day" (we watched favorite videos and made popcorn). We also made trips to the skating rink, the park for picnics, a local pond to feed ducks, the bowling alley, a big city shopping mall, the zoo, a matinee movie, a nature center, Erin's great-grandparents' home and Marine World. Other activities included cooking, computer games, dancing and art activities. I even invited a friend to join Erin's weekly trips to physical therapy.

It worked out wonderfully. Friends would look at Erin's calendar and decide if she was doing something they'd enjoy. Then they'd call and make reservations to attend. Some days, Erin had only one friend come over; other days, we hosted as many as 10. I canceled only one activity due to illness. At other times, if Erin wasn't feeling well, she'd just sit back while her friends played. Best of all, both Erin and I established deeper relationships with kids and their parents.

#### Back to school

When first grade started, many of Erin's kindergarten friends were in her new class. To help the children who didn't already know Erin, I attached a small photo album to Erin's chair. In it are pictures of Erin doing typical kid things—swimming in the pool, riding an adapted trike, holding her doll, cooking with mom, and doing things with friends. The photo album is very popular with the kids; nearly every time I'm at Erin's school, I see at least one child thumbing through it. It's a great way to let others know that despite Erin's obvious disabilities, she's still just a kid.

Donna Tatro lives in Magalia, California with her husband, Gordon, and daughter Erin, 7. Donna is actively involved in helping other families obtain needed services and full inclusion in their communities and schools. In her free time, she enjoys gardening, sewing and reading.

Dear Parents,

The first week after school let out was enough to let me know that I would need to organize some activities for Erin. She was one bored kid; Mom just doesn't make the best playmate! Phone calls to friends told me we weren't alone. Also I know parents assume that our circumstances I've never found that to be the case. Rather than me getting on the phone daily to find friends to come over or nized with already-planned activities.

I have invited other children with disabilities to join our club. I'd like the kids to understand that we all need ness need to be celebrated.

We treat Erin's disabilities in a matter-of-fact way. I'm happy to answer questions that the children raise (and I don't discourage them). You'll find that the children will have a matter-of-fact acceptance of Erin's circumstances--often sooner than adults. You should know that in our home they'll be exposed to a lot of different types of positioning equipment, such as walkers and standers, and therapeutic "toys." At Erin's bedside are three machines—a feeding pump, a suction machine and a nebulizer machine for breathing treatments; I've found that kids ignore these for the most part. Erin has "buttons" in her abdomen through which she's fed. I don't hide this from the kids; in fact, I encourage them to help. If your child tells you that he or she gave Erin a shot, don't worry, it's not true. Erin's medications are drawn with needleless syringes, then pushed through a "straw" into her tummy; I let the kids help with this. You're welcome and encouraged to come for a tour, to

The club will be an opportunity to develop and reinforce friendships with others. It may also be an answer to the summertime boredom blues. Even if your child does not join the club, please come to some of the special want to join in!

Donna Tatro



JULY 1995 / EXCEPTIONAL PARENT + 25



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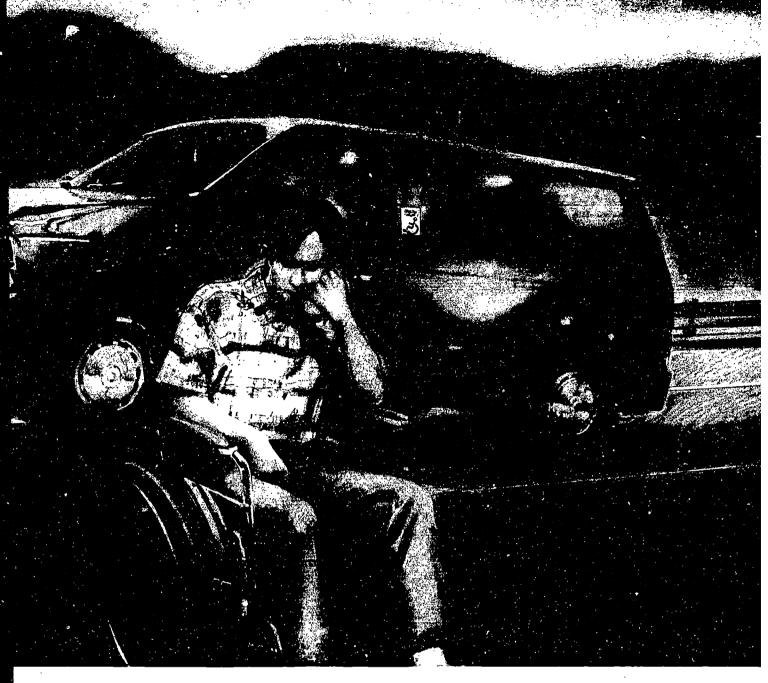
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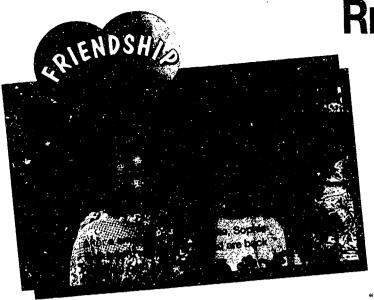
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READERS TALK ABOUT: Friendship

## Rescue 9-1-1

few weeks ago, my 10-year-old daughter, Sophie, invited a friend over to play at our house. Sophie is the only child with a disability in her school. This, however, has not stopped her from making friends in her class.

That Saturday, her good buddy, Shane, came over to play. At one point, Shane chose to stay upstairs and play while Sophie went downstairs to watch a video.

After awhile, Sophie got impatient.

"Shane!" she shouted loudly, "Come down here right now!" "No!" answered the indignant Shane, still involved in his Lego castle upstairs.

"Shane, if you don't come down here and watch TV with me, I'll call the police!" warned Sophie.

"Oh, Mister Tough Girl," replied Shane, valiantly holding his own.

"I am not a 'mister'," Sophie yelled up the stairs.

From the other room, I listened to this exchange with amusement, proud that my daughter was having a good old verbal knock-down, drag-out argument with another kid. Because Sophie was born with Down syndrome, I am always encouraged when she acts like the standard-issue 10-year-old, even if it means being crabby.

A few minutes later, after the argument seemed to have

#### READERS TALK ABOUT:

We invite you to contribute to the discussion in future issues of Exceptional Papers. In upcoming months, readers will be talking about:

- children's favorite toys and playtime activities (October; deadline Aug. 1, 1995)
- technology—how has it made a difference for your child? (November; deadline Sept. 1, 1995)
- grandparents/extended family (December; deadline Oct.1,1995)

Write to: Readers Talk, Exceptional Parent, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax). died down, I was setting hot soup and big crunchy crackers on the table for the kids' lunch. As they started to eat, there was a knock on the door, I opened it to my friendly neighborhood police officer.

"Ma'am," he addressed me formally, "Did someone dial 9-1-1?"

"Uh," I turned red,

"I think I can explain, Officer." I told him about the domestic quarrel between Sophie and Shane. Apparently Sophie had made good on her promise and, unbeknownst to anyone, had dialed 9-1-1, probably while I was making the soup.

From their seats at the table, Shane and Sophie could see that a real policeman was at the door. Sophie was looking halfway smug, as if to say, "See, Shane, I told you so..." but also halfway worried.

When I returned to the table, Shane, a look of shock on his face, was repeating, "Sophie, I can't believe you called the police!"

HAVING A FRIEND MEANS WORKING IT ALL OUT TOGETHER, EVEN THE WACKY STUFF.

AND THAT'S A LESSON FOR EVERYONE—NOT JUST FOR KIDS, AND NOT JUST FOR KIDS WITH DISABILITIES.

I took Sophie aside and reprimanded her. I told her that she should only dial 9-1-1 in an emergency—like a fire or if someone were hurt. In no uncertain terms, I let her know that she was not to call the police on her friends. She looked downcast and appropriately chastised and told me she understood.

Of course, in a perverse way that probably only another parent of a child with a disability could fully understand, I was thrilled Sophie could dial 9-1-1 and make the police arrive! Truth be told, sometimes I wish I could call the police on my friends—or my husband—when they won't do what I want.

The good news is that a little while later, Shane and Sophie went back to playing happily with each other, their friendship none the worse for wear. I guess that having a friend means working it all out together, even the wacky stuff. And that's a lesson for everyone—not just for kids, and not just for kids with disabilities.

---- Jolie Kanat Belleair, Florida



## **Just Friends**

It's Wednesday night, time to call Allison!
It's a regular part of Liz's midweek routine to call her friend and make plans for the weekend—just like any other
16-year-old girl.

For a long time, Liz's dad, her brothers and I wondered whether this typical teenage activity would be something Liz

would get the chance to experience. For years, we had been her "friends." We tried to do fun things with her—together and separately—that would fill her leisure time and give her something to look forward to. For a long time, this seemed to be enough. But as Liz grew older, it became clear that there was one thing all teenagers need that we could not provide for her—time away from her family. Then I heard about the Just Friends program.

Just Friends—a program of GOARC (Association for People with Mental Retardation and Other Developmental Disabilities in Omaha, Nebraska)—is a one-to-one friendship program that allows teens with disabilities the opportunity to interact with peers without disabilities.

Just Friends matches teens with disabilities to teens without disabilities. Matches are based on interests, ages and home locations. Volunteers without disabilities are asked to commit four hours a month for one year to the friendship. What the two indi-



See ya later, Mom! Liz (right) and Allison are on their way "out."

viduals do during this time together is up to them.

In addition to making one-to-one matches, Just Friends also sponsors several group events and activities every month. These events provide interaction activities for teens who are waiting for a one-to-one friendship. The group events also provide community involvement as Just Friends participants attend events for teens that are run by other organizations and members of other

organizations are invited to Just Friends events.

Liz was introduced to her current friend, Allison Holt, in April 1994. Liz, 16, attends the Madonna School for Exceptional Children. Allison, 17, is a junior at Millard North High School. Liz and Allison do something almost every week. The activity itself doesn't really matter. What matters is that Liz is able to get in the car, leave her parents at home where they belong and just "hang" with a friend.

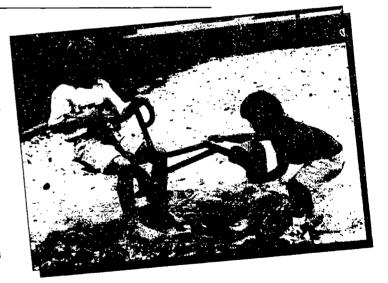
Liz has learned a lot from the Just Friends program and from Allison. She has learned how other kids her age feel and act. She has learned about loyalty and commitment. She has learned how to answer the age-old questions: "Where did you go?" ("Out") and "What did you do?" ("Nothing"). But, most importantly, she has learned what it means to have and be a friend.

— Jean Sigler Omaha, Nebraska

## **Appreciating Differences**

s special educators, my husband and I are committed to the inclusion of children and adults with disabilities—in schools, communities and the workplace. Our own daughter, Erin, does not have disabilities, but we wanted to instill in her an appreciation (as opposed to just tolerance) of differences in others. We knew that talking about diversity wasn't enough—Erin needed to have the experience of being around people who others might view as "different." Through exposure, we felt our daughter could develop friendships with a diverse group of people.

My husband and I have culturally diverse friends and friends with disabilities, so Erin has always had lots of exposure to adults who are different from Mom and Dad. But we also wanted Erin to be open to having friends with disabilities who were closer to her age. Those opportunities became available when Erin started kindergarten and a child with autism was included in her classroom. The kindergarten teacher created an atmosphere of acceptance through both



Erin Callahan, 6, and Michael Festino, 4, excavate a sandbox "construction site" at the local park.

word and action. This outstanding teacher treated Christopher as one of the gang, being matter-of-fact about his occasional need for extra attention.

One day, I visited the classroom during "circle time." As the other children sat on carpet squares listening to a story,

continued on page 30



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continued from p = 29

Christopher walked around the classroom. Erin saw me start to approach him and quickly intervened. "Mother, it's OK," she told me.

"Christopher *needs* to walk around some." I realized Erin was learning in her own way that children have different needs at different times.

RIENDS

During that same year, our family developed a friendship with another family that included a four-year-old boy with Down syndrome. I didn't feel the need to "set the stage" for the children's first meeting by explaining about Down syndrome. I wanted Erin to get to know Michael first; the questions would come later.

After spending some time with Michael, Erin asked me why he doesn't talk very much. I told her that some children have difficulty using words to talk; instead, they may use sign language, picture books or computers. Erin also asked if *she* could get Down syndrome. I explained that children are born with Down syndrome, that it is not an illness. I try to choose

my words carefully so as not to diminish the person with a disability; I also want to be sure that my explanations don't make Erin afraid to interact with another child. In fact, Erin and Michael have become great friends. They enjoy going places with each other and spending time at the other's home.

Here are some suggestions I'd give other parents who are trying to facilitate these kinds of friendships:

- Answer questions. Don't make a child feel embarrassed about asking questions. When answering questions, be honest and direct.
- Avoid labels. Instead, describe the child with a disability in positive ways. Instead of saying, "Johnny doesn't talk," you can say "Johnny talks with his hands."
- Make inclusion a regular habit. Take advantage of everyday opportunities such as birthday parties and weekend outings to include children with differences, so friendships have a chance to grow.

— Teresa R. Callahan Ocean Springs, Mississippi

## Special Friendships

ately, friendship has been one of my top concerns for both of my children, one of whom has severe physical, intellectual and visual disabilities. In meetings with other parents of children with disabilities, I find they are also preoccupied with the "friend situation." I think many of us have started thinking about friendship because the inclusion movement has made us question *all* the limits placed on our children's lives, whether or not our children are involved in "inclusive" education.

I am troubled, however, that other parents rarely consider other children with disabilities as potential friends for their children. We expect parents of "regular" children not to discriminate against our children, but we discriminate against them ourselves. I'm not saying that the friendships of a child with special needs should be restricted to other children with disabilities, but I strongly believe that the possibility of such friendships should not be dismissed.

My four-year-old son, Isaac, has such severe disabilities that the other children who attend his special education program do not provide friendship opportunities in the usual sense. It is clear, however, that he enjoys their company. His teacher tells me that he constantly approaches his classmates and attempts to initiate social interaction. Sometimes, he and another child will sustain an ongoing interaction for a fairly extended period. It is distressing to me that the parents of these classmates do not seem interested in trying to support these "friendships" outside of school.

I have been fortunate to become friends with the mother of a boy who has disabilities somewhat less severe than Isaac's. This mother has also been interested in promoting friendship between our sons. Isaac and her son, Brian, enjoy each other's company and meet each other's needs in ways that "regular" friends might not. Both boys enjoy a level and type of physical contact that is not typical of boys
their age; they also
enjoy many of the
same play activities.
I know the other boy
looks forward to his
play dates with my
son and likes having
a true friend. And if
Isaac could communicate such an abstract
thought, I'm sure he
would say the same.



Isaac Sugar, 4, (le.t) enjoys playing with Brian Matsumoto, &

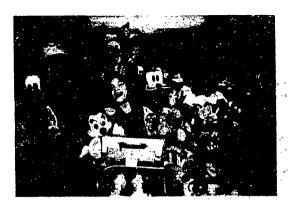
I don't mean to say that my son cannot be friends with a child who does not have disabilities. Isaac certainly enjoys the company of "regular" children. He also benefits from exposure to children who use language well and behave in an age-appropriate manner. In return, Isaac offers these children an enjoyable experience free of competition and aggression. He is unreserved about expressing affection and admiration. These children may also learn that the differences between themselves and my son are not so great as they may first seem.

I certainly hope that Isaac will have good friends in the years ahead. I fully expect that many of those friends will have some sort of disability. Having a friend with disabilities does not make Isaac more "disabled," any more than befriending my son would reveal a failing in a "normal" child. My goal for Isaac is the same as my goal for everyone else in our family—to be open to friendship whenever an opportunity presents itself, and to create such opportunities whenever possible.

—Lynne Tamor West Bloomfield, Michigan

#### familiar faces





When these friends hit the mall, the Disney Store is their first stop. Angela Hope Litterilla, 14, is surrounded by (from left) Brittney Otterback, Kathy Reyna, Hillary Bertran-Harris, Claire Andrews, Trish Howard and Nicole Myers. Friends since the fourth grade, Angela and the rest of the crew are now in junior high school. Angela, who lives in Oceanside, California, has cerebral palsy and uses augmentative communication.



Checking out the underwater creatures at the National Aquarium in Baltimore, Maryland are (from left) Stephanie Nelson, 6, Caleb Nelson, 8, Kyle Laursen, 6, and Kallin Laursen, 3. Best buddies Caleb and Kyle have achondroplasia, a form of dwarfism, and see the same doctor in Baltimore. Their parents try to coordinate the boys' medical appointments so the friends can spend time with each other during these mini-vacations. The Nelsons live in Columbia, Missouri; the Laursens live in Springfield, Missouri.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issuel

David Onwukwe, 5, shows his affection for next-door neighbor and best friend Joshua Chartienitz, 10. The boys, who live in Washington, DC, enjoy playing with toy cars and trucks on the sidewalk,



splashing in Josh's wading pool and passing cookles, candy and other treats through the fence between their homes. Joshua has cerebral palsy.



Best friends Kelsey Welch (left) and Lyle Eldridge, both 9, enjoy Lyle's birthday bash. It was no surprise that Lyle chose to celebrate his birthday at Pizza Hut—he's a big fan of Italian food! Lyle, of Montrose, California, and Kelsey, of Quartz Hill, California, have Down syndrome.

Eight-year-old Adam Maione (left) and best friend Jimmy Dio, 6, strut their stuff in a class production of "Sentimental Journey at Anna McCabe Elementary School in Greenville, Rhode Island. Adam's mom, Diane, says that Jimmy can always be found beside Adamexcept when he's behind him, pushing Adam's wheelchairl





624

#### rathers' Voices

## **Grocery Baggage**

by Timothy Perry

do diapers. Lots of them. I wash dishes, do laundry and wipe runny noses. I take my daughter, Chelsea, to therapy sessions and doctor appointments. So it was no surprise—to me anyway—that this father might be grocery shopping with his daughter one busy Saturday morning at the local mega-market.

"Excuse me..." came a tentative voice from behind me in the checkout lane. I turned to see a silver-haired woman in her mid-fifties.

"I couldn't help but notice. Does your daughter have something wrong with her legs?"

Chelsea sat in the grocery cart. She was grinning wildly and sucking up eye contact like a Kirby upright, but three inches of orthopedic bracing were plainly visible to anyone who cared to look.

"She has spina bifida," I offered.
"Chelsea can't really walk on her
own."

I wondered if this woman would react as so many others have... by abruptly ending the conversation without uttering another word. Confronting disability turns many people instantly mute. It's an all too common response, but one to which I have always tried to be empathetic. After all, two and a half years ago, I was walking in their Reeboks.

"Oh my. She looks so... healthy." "She is, really!" I declared.



Chelsea is as bright, intelligent and cheerful a toddler as any I know. She exhibits none of the physiological cues that point to conditions like Down syndrome or cerebral palsy. Seated in a grocery cart, there is little to indicate she has any problem at all... unless one spots those braces.

"I'm afraid I don't know what spina bifida is," the woman volunteered,



Two-year-old Chelsea graciously accepts the obligatory peck on the cheek from twin brother Patrick. According to Dad, a bit of sibling rivalry has flared in the two years since this photo was snapped.

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their chiles's and families' lives.

her tone suggesting a fair bit of apprehension.

"That's OK. When she was born, neither did I. But you can bet I do now!"

So... just how much to tell this woman? We were in a short checkout lane and this could turn into a very long story. But both my wife and I had done this before—hit the high points and if they ask, deliver additional information on an as-needed basis.

I explained that a child with spina bifida is born with a hole in the spine. As a result, a lot of normal nerve connections never reach their appointed destinations. The severity of spina bifida can vary widely, from nearly total incapacitation to extremely mild physical effects. Chelsea's condition fell somewhere in the cavernous middle ground.

Then I stopped and pondered what this woman's reaction would be if I told her the whole story. Chelsea's inability to walk is but one ramification of our family's situation. I could have talked for hours about the endless surgeries, physical therapy sessions and doctor's appointments; about the medical bills-big enough to rival the GNP of some third world nations; about the fears that rage inside me like caged demons. There exists an overpowering downside to Chelsea's medical condition, but most times, I only see the upside to life with my daughter.

Significant parental bias aside,

continued on page 34

## The Events That Make a Difference

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continued from page 32

Chelsea is strikingly beautiful. Once establishing eye contact with a likely victim, she locks on like a pair of vise grips. Perfect strangers are drawn to her gaze... and Chelsea had sunk her hooks into this woman from the get go.

I explained that I really felt quite thankful. Chelsea is a very happy little girl. Her condition is nowhere close to

a worst case scenario and the long-term outlook is as bright as can be expected under the conditions.

"But she'll grow out of it, right?" the woman asked optimistically.

Children grow out of a great many thingscolic, ear infections, teething. But unfortunately, spina bifida isn't among them.

"No, I'm afraid she won't."

"Oh don't you give up hope now! Doctors are doing incredible things these days. You never know! Maybe somedav..."

Her voice trailed off as my mind revisited familiar terrain. Plenty of things can be done to help someone with spina bifida. Wheelchairs, speciallyequipped vehicles and other gadgetry

> are available to smooth off the rough edges... but there exists no cure. Not now. maybe not ever.

> "...It really is amazing to see the progress they're making. You just keep praying, okay?"

> I looked into her eyes, genuinely touched by the compassion of this perfect stranger. She stood in sharp contrast to the cashier

Mom and Chelsea, 3, engage in some high-speed travel around the neighborhood.

whose eyes had remained transfixed on the floor tile throughout this entire conversation.

I pushed my cart forward. then turned. "Keep praying? I wouldn't know how to stop! Comes with the territory. I do



day of preschool in September 1994.

diapers, too. Did I mention I do diapers? And runny noses... lots of runny noses!" EP

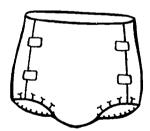
Timothy A. Perry, 39, lives in Waterford, Michigan with his wife, Jackie, and their children, Lauren, 6, and twins Patrick and Chelsea, 4, who has spina bifida and hydrocephalus. Timothy is a free-lance feature and advertising writer, producer and voice talent.



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## **Building Community Resources**

Enabling inclusion in community programs and activities

by Serena Umstead, Kimberly Boyd and Carl Dunst

ommunities can provide an extensive array of opportunities for children and families to achieve social and emotional well-being. These opportunities may include such community resources as swimming lessons at the YMCA, drop-off child care programs at local churches, library story times and soccer teams. These activities bring us out of our homes and connect us to one another.

The Building Community Resources project of the Child and Family Studies Program at the Allegheny-Singer Research Institute in Pittsburgh, Pennsylvania is developing and testing strategies to support full community participation by children with disabilities and their families. The project is working with families in two very different Pennsylvania communities. One is a small industrial town that has experienced difficult economic times; the second is a developing bedroom community on the outskirts of a major metropolitan area.

The goals of the project are to identify available programs and activities in the community, to enhance the capacity of these programs to involve all community members, and to foster enjoyable family participation in these community programs and activities—day care centers, neighborhood organizations, churches and synagogues, recreation centers, libraries, parks, pools and playgrounds, hospitals and health centers, museums, sport leagues and scout troops.

Benefits of community participation Although many families receive support from professionals working with their children, participation in "special" programs may actually contribute to a family's sense of isolation from their community. Although the support of service providers can be valuable, families who are involved in community activities can also access support, assistance and encouragement in the same way as their neighbors. When problems arise, they can look to friends, neighbors or fellow church members.

Community involvement allows families to build relationships that do not focus on a child's disability or difference. For example, one parent involved in the project said she particularly enjoyed the friendships she made while waiting for her daughter Lakeisha at swimming and gymnastics classes. She told us that when she ran into these other parents at the supermarket or mall, they had many things to talk about, including their children's accomplishments and activities.

Parents also talk about the benefits of giving other community members the chance to know their child and family. Other children come to understand that children with disabilities share many of their own talents and interests. Children who play and learn together develop respect for each other's abilities.

#### Making it work

The first step in building community resources is to identify or "map" community assets. This process starts by identifying your family's goals and aspirations—the experiences you would like your child or family to have. Next, identify the types of programs or activities that would meet those goals, along with the supports your family or child might need for participation. Finally, use various information resources—printed information and information provided by other members of the community—to identify potential activities and supports.

For example, the parents of an eightyear-old child with cerebral palsy were interested in swimming lessons for their daughter. Unfortunately, the pool at the local recreation center was not equipped with the lift that would be necessary to get eight-year-old Carley safely into and out of the pool. Using the mapping process, Carley's parents identified a number of civic and philan-

thropic organizations; when asked.



On the beam:

Doug Umstead (right) enjoys participating in a community gymnastics class.

------

one of these groups was willing to purchase the needed equipment.

The Building Community Resources project has talked with a number of families who have a history of successfully accessing community programs for their children with special needs. We asked about the strategies they used. Here are some things they told us:
• Finding resources—Families often did a lot of legwork to identify appropriate programs for their children. They sometimes learned about activities through the phone book or local newspapers, but more often found out about community programs from other families and friends.
• Providing information to my.

 Providing information to programs—Many families chose not to reveal their child's disability during the first contact with a program. For some families, the information they provide depends on the circumstances; many provide only the information needed to make successful adaptations of particular environments and activities.

• The importance of "key players"—As a general rule, successful participation in a particular activity depended on the attitude of the person having the most direct contact with the child with a disability. Many families spoke glowingly of individual swimming instructors, gymnastics coaches or preschool teachers; others spoke of difficulties encountered in similar settings but with different individuals.

#### The program in action

Using what we have learned from the experiences of successful families, the **Building Community Resources staff** helps other families explore involvement in community activities. Once a family chooses or targets an activity or program, the family decides how the project staff might help. Some families just need a few phone numbers to get them on their way. others might want to brainstorm for strategies to increase a child's participation at a local library or playground.

In such cases, the project staff mobilizes an informal community "team," bringing together the family and community members to develop and test various strategies for successful involvement. Strategies may focus on sharing information about the child, ensuring safety, building friendships, making physical adaptations or securing funding.

In the case of Carley's swimming lessons, for example, her parents and the swimming instructor were concerned about Carley's physical safety. Together they decided that an additional person in the water would be the best solution-someone who could focus specifically on Carley's safety. The last thing Carley wanted was to "stand out" by having her mother in the pool, so the team considered other people who might be available and more appropriate. As it turned out, one of Carley's favorite cousins happened to be working at the pool for the summer so she was available and happy to assist. The instructor was pleased with how

#### Inclusion at the Library

want all three of my children to love books and enjoy reading. I have always taken my older children to the library, but I kept my youngest child, Joey, at home for the first few years of his life. Then, on one of Joey's first trips to the library, one of the librarians yelled at him, even though I was trying very hard to help him limit his loud outbursts and running.

I called the Building Community Resources team for help. They asked what I wanted: I told them I wanted that particular librarian to "loosen up." I also wanted to play a behind-the-scenes role in their initial contacts with the library. I did not want to tell the librarian about loey's diagnosis because I thought she would only see the label and not the child. I asked that the Building Community Resources team contact the library in such a way that nobody would make an association between my child's behavior and the contact.

The team met with the children's librarian to introduce the Building Community Resources project. They offered their problem-solving services to help the library make the children's room and activities accessible for all youngsters in the community. The team also asked about strategies the library staff had found helpful for including children with differing abilities.

During this conversation, the librarian mentioned the library's concerns about including children with behavior management challenges. In response, the team was able to talk about the possible causes for difficult behaviors and offer some strategies that have proven helpful for children and families in similar circumstances.

After this meeting the team got back in contact with me and suggested I begin a dialogue with this librarian to explain how much I value the library's programs and why I want all my children to be active at the library. Using team members as facilitators, the librarian and I began working together to find ways for all my children to use the library regularly and for my youngest child to start attending story hours. I feel really good that I was able to work things out with the librarian and that my son will be able to participate in children's room activities.

-Jody Wenzel Pottstown, Pennsylvania

smoothly the class went, and having a helper in the pool allowed her to spend more time with each child.

#### Focusing on similarities

The successes of the families we have worked with thus far are especially encouraging. Perhaps most encouraging is the willingness of community members and organizations to accommodate families' desires to have their children participate in community activities.

The Building Community Resources project stresses the similarities between children with and without disabilities. Focusing on similarities rather than differences places the emphasis on shared experiences. This is not to say that disabilities are ignored. Rather, supports are put into place to minimize the effects of the disability so the entire community can enjoy the benefits of shared experiences.

Serena Umstead is the mother of Tenzin, 12, and Doug, 5, a child with special needs. She is a community resource coordinator in Pottstown, Pennsylvania for the Building



Danny Burke (right) enjoyed participating in a weekend Cub Scout campout with other members of his den.

Community Resources project of the Child and Family Studies program of Allegheny-Singer Research Institute in Pittsburgh, Pennsylvania.

Kimberly Boyd is co-director of the project. Carl Dunst is a senior research scientist with Allegheny-Singer Research Institute.

Also contributing to this article were team members Holly Shields-Menegazzi, Tina Bode and Danielle Sauer:

## **Mostly For Kids**

**Books and Videos About Living With Seizures** 

#### Lee the Rabbit with Epilepsy

By Deborah M. Moss Woodbine House, Inc. 1989

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This brightly illustrated picture book follows the adventures of a small rabbit who has seizures. It tells how Lee and her family cope with the challenges of epilepsy, beginning with Lee's first seizure and initial visit to the doctor, through her diagnosis and treatment. Use it to explain epilepsy to your child with epilepsy, as well as brothers. sisters, and friends. Ages 3-6

Catalog # 133LRB 23-Page Hardcover Book \$12.95

#### Mom, I Have a Staring Problem

A true story of petit mal seizures and the hidden problem it can cause: Learning Disability By Marian Carla Buckel and Tiffany Buckel 1994

Tiffany, a seven year old, describes her experience with petit mal seizures: her feelings, wishes and fears. Written to help adults recognize a hidden problem that could be occurring with a child who has learning problems.

Catalog # 220MSP 24-Page Softcover Book Julia, Mungo, and the Earthquake

Imagination Press, 1991

Children who have epilepsy are frequently teased and rejected by other children. This book tells the story of a young girl with epilepsy who becomes the school heroine. It addresses barriers that children with epilepsy confront and can help improve the self

Catalog # 209QKE 47-Page Softcover Book

#### Dotty the Dalmatian has **Epilepsy**

From the Dr. Wellbook Collection Tim Peters & Company, 1993

A delightful illustrated story for young children. This is the story of Dotty the Dalmatian who discovers she has epilepsy. At first Dotty feels embarrassed and afraid, but once she learns to accept and control the seizures she happily goes back to her important job helping the fire fighters save lives. Ages 2-6.

Catalog # 208DDB 16-Page Softcover Book \$4.95

#### Spider Man Battles the Myth Monster Let Spider-Man help you battle the Myth Monster!

Spider-Man helps bring truth and justice to the lives of three children with hidden health conditions: epilepsy, asthma and diabetes. This comic book is an excellent resource for anyone working with children. It encourages acceptance and understand-

ing among all children. Ages 8-11. (1991) 16-Page Comic Book

A Story for Young People About Epilepsy

By Saxby Pridmore, MD and Mary McGrath

esteem of the child with epilepsy. Ages 6-12.

Brothers and Sisters: A Guide for Families of Children with **Epilepsy** 

I Have Epilepsy Too

Yo También Tengo Epilepsia Winner of the CINE Golden Eagle Award Introduce your child to other children with epilepsy.

"I Have Epilepsy Too" interviews nine children with epilepsy who discuss their experiences with seizures and coping with the physical and emotional aspects of epilepsy. The primary message is

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# 529IHF (Spanish)

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"Brothers and Sisters" is divided into two sections. The first half is written specifically for siblings to read with separate sections based on age. The second half of the guide is written for parents and other adult family members (aunts, uncles, and grandparents) to help them understand and handle sibling concerns. (1992)

Catalog # 172BSF 95-Page Guide

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#### Nick and his community experience a very special basketball game



f someone had told me when I was pregnant that my son would be on a championship basketball team, I would have been proud. If someone had said the same thing when Nicholas was two. I would have cried, thinking it the cruel joke of a heartless person.

Nicholas is 14 now, but since the age of 18 months, doctors, therapists and special teachers have been a big part of his life. Nick has a severe speech disorder, mild mental retardation and mild to moderate fine- and gross-motor delays. When Nick was two years old, a doctor told us he didn't know how well our son would walk—if he walked at all. Twelve years later, although his gait is awkward, Nick walks, in fact, as a participant in the 1990 New Orleans Crescent City Classic junior road race, he ran a mile in just over 13 minutes. And, although it might have seemed an impossible dream 12 years ago, Nick has indeed played basketball with the Nuggets, a local team that won playground championships in 1992 and 1994.

A special season

The 1994 basketball season was very special. The camaraderie and sportsmanlike conduct exhibited by Nick's peers far surpassed my expectations. Whenever the team was ahead. Nick's teammates would make significant efforts to give him the ball, allowing him opportunities to make shots.

On one such evening, Nick's teammates gave him repeated chances to make a shot. Each time, they'd get the ball and head down the court. Nick stood in a designated spot beneath the basket, surrounded by his buddies. The center would drive the ball down and pass to Nick. Then, with his whole team guarding him, Nick would attempt a shot.

That night, despite several attempts, Nick had still failed to make a basket. Either he missed, or a player on the opposing team managed to block the ball. Nick's teammates moved him closer to the goal for a few more tries. Still no luck. Then it happened... not only did Nick's teammates rally around and guard him, but—quite visibly—the players on the other team backed off, allowing Nick time to set up and try for the shot. When the ball swished through the net, not only

did Nick's team cheer and applaud, so did the other team. all the players on the benches and all the moms and dads in the bleachers.

#### Years of exposure

How did this happen? How did an entire community reach the point of being able to show such unselfish support to a member with a disability? It didn't happen just during that one game or one season. It took all 14 years of Nick's lifeyears of exposure to the community, years of living and going to school in our neighborhood.

Mike and I have always seen Nick as a child who just happened to have a disability. Although our dreams for Nick were severely altered, we never stopped having expectations for his behavior and his participation in the community.

> We have used the everyday activities of our lives to teach Nick independence. Grocery shopping, banking and even voting offered Nicholas new opportunities for learning in the community.

> > Each year, we have adjusted his daily school schedule to include more or different opportunities for Nick to be around peers without disabilities.

with the school system to keep Nick with the same group of students from year to year. This has allowed him to develop close relationships with classmates, relationships that paved the

way for the establishment of very natural supports. We took chances. Before basketball, there was a year of gymnastics and a few seasons of track. When Nick participated in the AWANA Club at our church, a Christian boys and girls program like

Boy Scouts, he was allowed to move at his own pace and receive appropriate support and adaptations in earning badges.

When he started playing basketball, Nick was allowed to play on a team of younger players. Nick wasn't always readily accepted, but we kept exposing the community to the challenge of our differences and expectations.

No, that special night on the basketball court didn't just happen. The families in the bleachers and the

continued on page 40

Championship Season Furthermore, we have negotiated

by Rose Gilbert



JULY 1995 / EXCEPTIONAL PARENT *

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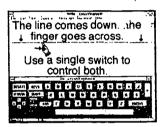
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Circle #80

continued from page 39

young boys on the basketball court had known Nick for years. They'd attended school with him, and seen him at the bank, at the grocery store, at McDonald's, at church, at the gym and throughout our community.

#### Life lessons

Months after basketball season ended, I was waiting in line at a fast food restaurant when Nick turned to a stranger and said, "I'member you!" This "stranger" turned out to be the mother of one of Nick's teammates, the boy who always set up the shots for Nick. She conversed with Nick for a few minutes, then turned to me and told me how special she thought those games had been.

Another mother shared what her son had said about the night his team, several points behind in the game, had relaxed their guard and allowed Nick to keep trying until he made that basket for the opposing team. "Mom," he'd told her, "that was the hardest thing I've ever done." But just think of the life lessons those boys were learning that night!



Joining Nicholas for a backyard basketball game are (from left) cousin Danny Porter, Nuggets teammate Chester Schwall and Sunday school friend Jonathan McGee.

We would advise other families to hang in there, take chances and be realistic. We continue to work toward our goal of independence for Nick. Each year of school and community involvement has built on lessons learned the year before. As always, we continue to focus on Nick's strengths—his strong sense of direction and love of people. The successes we've experienced thus far have been grounded in these strengths. EP

Rose Gilbert lives in Harahan, Louisiana with Mike, her husband of 18 years, and their two sons, Nicholas, 14, and Aaron, 4. Rose is director of Families Helping Families of Greater New Orleans (FHF of GNO), one of a network of nine family-directed resource centers in the state. Rose has also been co-director of Project PROMPT, Louisiana's Parent Training and Information Center, a program of FHF of GNO.

## Respite Care and the Religious Community

by Bill Van Dyken

remember well the astonished response—"Do you mean someone from our church would actually call and invite my child over to their house?"

"Yes!" I replied with certainty. The mother's face brightened, and then saddened.

"No, I don't think so," she said softly. "No one from our church has ever asked our son over. In fact, I really don't think anyone cares."

I think about those words of resignation every time I hear of a family who has a child with a disability and needs community help to give them some time off from the demands of caring for their child. These words are far too common among families who have been faithful members of their religious group, but feel lonely and abandoned by their faith community. I can sym-

> pathize with the family who desperately needs help-we, too, have a child with a disability. But because I am a pastor, I can also identify with people in the faith community who at times may seem unhelpful and uncaring.

People in the religious community do care, but they sometimes lack the knowledge or organizational skills to carry out that care. Yet, with the right promotion, urging and organization, religious communities can provide respite care in an effective way.

In the last five years, I have worked with 20 different religious groups to set up respite programs. Out of those 20 pro-

grams, about half are still operating.

Kathy Schreurs (right)

describes her first experience

Now, she is one of Katie's

favorite caregivers.

with respite care as a "disaster."

Of course, situations change—people move and other avenues of respite open up, such as government-funded pro-

grams. For the most part, however, the longer-running programs are those that have an active committee in the congregation continuing to monitor and promote respite care.

Organizing respite for Katie's parents Dean and Laurie had not been in town very long, but had heard about a program for family respite. Their daughter, Katie,



Although the Gabhart family-(clockwise from left) Dean, Laurie, Jeff, Katie and Tim-was new to their congregation, 15 volunteers came forward to provide respite care for Katie, who has Sotos syndrome.

Ron, the couple's pastor, was more than willing to be involved in recruiting volunteers and helping with the necessary organization of the program. I offered to help him by speaking to potential respite providers. Fifteen possible

volunteers attended the first organizational meeting. Laurie later commented, "As relatively new members of the church, we were overwhelmed by the response and encouraged by the willingness of people to help us out."

Before the organizational meeting took place, I asked Pastor Ron if he knew of someone who would be willing to coordinate the program. Church member Pam Wright agreed to take on that role. Her job would be to phone volunteers and send out written reminders before each respite visit. This was to occur twice a month initially; if there was a need for additional respite, Dean and Laurie could ask for more help.



At the organizational meeting, we spent most of our time talking about what it means to take care of Katie. Her parents and teacher shared their insights on Katie's needs. We discussed Katie's habits, likes and dislikes and ability to adjust to new situations. (Katie's medical needs were minimal, but in other cases, it may be helpful to invite a medical professional continued on page 43



Volunteer Lorraine Roorda (left) admits to some initial reluctance to volunteer for the respite program. But with the encouragement of husband Hessel (right), she gave it a try. Now she says, "My confidence in caring for a special child has grown. I have the satisfaction of doing something to give Katie's parents a short break and I have gained some new friends as well."

#### Steps to a Successful Respite Program

- Compile a mailing list: Work with local agencies to compile a mailing list of families who have children with disabilities.
- . Determine community interest: In cooperation with cooperating agencies, send out a survey asking parents if they would be interested in respite care through their faith community.
- Provide details: Tell interested parents about the use of volunteer respite providers in religious congregations. Explain that recruitment of these volunteers and a program coordinator will be handled through the religious group, but that they have the final say regarding choice of volunteers. Ask permission to contact their faith leader.
- Inform faith leader of family's need for respite: Tell the leader of the family's congregation about the use of volunteers as respite providers. Ask him or her if there is an existing group in the congregation that might be willing to take this on as a project.
- Develop recruitment strategies: With faith leader or working group, decide on the best way to recruit volunteers. Ideas may include bulletin announcements (if parents feel comfortable with this approach), personal appeals and speakers—parents from other congregations who are current respite users may be especially effective speakers.
- Find a program coordinator: Get someone who is compassionate, available for calls and, preferably, unrelated to the respite-using family. The congregation's secretary or a senior citizen who is usually at home and

near the phone may be ideal for this role.

- Set up an organizational meeting: Do this after at least six potential volunteers have signed up. Have volunteers meet with the parents, the child and, if appropriate, educational and/or health care professionals. It is helpful if a child's parents and other professionals can provide written information about the child that can be distributed to volunteers.
- Set up guidelines with parents: Make note of the times, places and frequency of respite the family is seeking. Remind parents to go through coordinator for all respite needs.
- Set up guidelines with program coordinator: The coordinator will make all respite arrangements. If parents have need for additional respite, the coordinator can make arrangements with volunteers. Have coordinators send reminders to providers before each scheduled respite time. Make sure all respite providers have the coordinator's phone number.
- Promote congregational awareness: It is important that the religious community feel a sense of "ownership" of the program. An article in the faith group's publication, notes of appreciation to respite providers and public mention of the program from the faith leader contribute to congregational awareness and this feeling of ownership.
- Evaluate program: Evaluate a new program within the first three months. After that, do it every six months. Check with the parents and the coordinator to see how well the process is working.

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Circle #77





635

continued from page 41

to the organizational meeting to provide an overview of a child's medical condition and special needs. In some cases, respite volunteers may need to learn special techniques to care for a child with complex medical needs.)

We talked about the need to start slowly with Katie, letting the newness of these visits be short. We also spoke about where respite care should take place—a decision that needs to be made by individual families. Katie's family decided that she should be cared for outside of the home; this would allow Dean and Laurie to spend more time with their other two children.

#### Positive experiences for volunteers

A few volunteers will eventually become "favorites" for the child and family. Katie is particularly fond of Kathy, but this did not happen overnight. In fact, Kathy recalls her first official respite experience as "a disaster"—"When I went to pick Katie up, she clung to her father and was very emphatic about not wanting to go out with me. 'No!' is a pretty clear word. Katie was upset, her father was embarrassed, and I was devastated."

It took Kathy some time before she felt ready to try again. But after a few visits with the entire family, including a trip to an ice cream parlor, Katie decided outings with Kathy might be fun. Now they regularly enjoy a variety of activities together—attending basketball games, going to the mall, baking cookies and feeding Kathy's guinea pig.

Lorraine, a 70-year-old grandmother, was initially reluctant to be part of the respite program. She remarked, "Even though I had a desire to help, I decided I was not capable of caring for Katie." But when Lorraine's husband offered encouragement, she decided to give it a try. Now Lorraine reports, "This has been a good experience for me. My confidence in caring for a special child has grown. "

Responses from other volunteers have been equally positive. Arlet, a special education teacher, commented, "Being involved in the respite care program with Katie has given me a way to use the abilities God gave me and help friends in the process."

#### Kids also benefit

Respite not only gives parents a much-needed break; the program may also provide their children with socialization experiences. As Dean and Laurie put it, "Respite has allowed Katie to experience more and varied social situations and to become more accepted as a member of the church and community."

When I hear discouraging words from parents who have given up on their faith community, I think about the words of other parents such as Derrick and Marla who wrote: "We have greatly appreciated the respite program through our church. The members of our respite team are very willing to help us out when needed and seemed to have gained as much as we have in building a relationship with our family." **EP** 



Bill Van Dyken is an ordained postor and chaplain in the Christian Reformed Church. Since 1987, he has been religious services coordinator at Hope Haven in Rock Valley, Iowa. Hope Haven, a rehabilitation and housing

#### The Power of Love

hen Bob and I got married, he knew he was getting a "package deal."

Along with me came my sons—Matthew, a lively, verbal six year-old who loves to be the center of attention, and Brandon, 4, who has been diagnosed with pervasive developmental disorder (PDD) and autistic tendencies. We thought we knew what we were getting into, but neither of us was prepared for the amount of adjustment it would take to become a "family."



A "package deal"—On their wedding day, Teri and Bob Mika pose with their ready-made family, sons Matthew, 6, and Brandon, 4.

"It's just going to take time," we told ourselves. But within a few months, we realized things were getting worse instead of better. Bob felt rejected by the boys and neglected by me. I was overwhelmed; I felt like I was taking on responsibility for all the relationships in the house. I was constantly exhausted from work and worry. The boys were showing their frustration with our awkward first attempts at parenting together.

We first heard about the respite program through our area education agency. Initially, the thought of asking for help filled us with apprehension. When Pastor Bill spoke to our congregation and asked for volunteers, I was sure the sign-up sheet would stay empty. Then we found out that 12 families had volunteered! We were relieved and filled with joy; we were being heard and understood instead of judged. Just knowing that other people were willing to help did a lot to make us feel better about ourselves as a family.

The program has worked well for us. Each volunteer family is different, so we ask what they feel comfortable doing the first time. Some begin by coming to our house to ask questions and meet Brandon. Others seem comfortable just "taking the plunge," so we go ahead and drop Brandon off for a visit. So far, every home has had something to spark his interest—an interesting video, a dog, pigs, cows, pizza or a person with blonde, straight hair (a special favorite with Brandon).

The respite program gives us the chance to attend a support group once a month without having to find a sitter who "can handle" Brandon. Volunteers will also take Brandon just to give us a break or allow us spend some time with attention-starved Matthew. And a few families have gone beyond the call of duty and cared for both boys, giving Bob and me some much-needed time with each other.

We're so thankful for these people who so willingly give their time and love to our son. We were initially surprised that our church was so open to this program, but we have come to realize that we can never underestimate the power of love in God's people.

—Teri Mika Inwood, Iowa

agency, has served people of all ages with intellectual impairments for more than 30 years.

Bill edits PASTOR TO PASTOR, a quarterly newsletter for area churches. He is a board member of the Christian Council on Persons with Disabilities. He and his wife, Barbara, live in Rock Valley with twins Matthew and Lora, 16. Their oldest son, Mark, is married and lives in Fort Wayne, Indiana.



## Integrated Neighborhood Playgroups

Creating an environment where friendships can blossom

by Trudy Marsh Grable

and heartbreaking Sunday afternoon that I started my first journal. I had heard others say that keeping a journal is therapeutic, and desperate to rid myself of the frustration and sorrow I felt, I purchased a blue, paisley print, hardcover "blank book." Eager to begin this ten-dollar therapy, I put pen to paper and began writing—awkwardly at first—about my feelings and difficulties as I worked at the daunting task of integrating my little blonde beauty into our world.

My daughter, Lauren, experienced her first seizure at three months of age. It was not to be her last. She was eventually diagnosed with an epilepsy syndrome known as Lennox-Gaustaut, along with developmental and language delays. Her behavior was unpredictable, impulsive and often invasive. The neighborhood children who came into contact with Lauren were hesitant and sometimes fearful of her unpredictable nature.

On the day of my first journal entry, I felt particularly defeated. It was the second or third time I had taken Lauren to Sunday school. Katherine, the Sunday school teacher, was very willing to include Lauren in the class; I'd stayed to assist her. Sadly, it became apparent to me that this was not working. Due to Lauren's disruptive and distracting behavior, I needed to remove her from the classroom repeatedly. I recall standing outside with Lauren. peering through the classroom window and praying that she would someday acquire the skills I saw developing in the other children, Although this group of children was one to two years younger than

Lauren, the developmental gap seemed insurmountably vast. I left, feeling hopeless and heartbroken.

At home, I wrote in my new journal—"I think I will start a neighborhood playgroup." I never could have imagined the sequence of events that would follow—or their positive impact on Lauren, our family and our neighborhood...

#### **Getting started**

I had no road map for beginning this venture, but I forged ahead. Although Lauren did not play with other children, I knew she needed socialization and exposure to the behaviors of typically-developing children. Other mothers become Girl Scout leaders for their daughters; I became a playgroup facilitator so that my daughter could participate in her community.

I decided the playgroup should meet on Friday mornings. I began by inviting two neighborhood children, one boy and one girl, both younger than Lauren. To their parents I explained my motivation and plans for the group. Another neighbor, Sherry, provided child care for neighborhood children; she became a great resource for identifying additional children to include. When one of our regular kids became ill and unable to attend, I would invite one of the children at Sherry's. Eventually, they all became regular members of our group. On school holidays, we would invite their older siblings to join us. They became my "helpers."

The fear of failure was especially present in the early weeks of Lauren's playgroup. Not every session went smoothly. This would make it difficult to prepare for the following week. But my fears slowly resolved as I began to realize that the sessions, no matter how I felt about them, were well-received by the children.

#### Growing pains

My biggest challenge was to watch the developmental gap widen between Lauren and the other children. It was never easy to watch the younger children's abilities surpass Lauren's. Many times, those feelings made me think about bringing the group to an end.

I was forced to reexamine my goals—this group was for Lauren, not for me. No matter how I felt, I had to realize that the benefits Lauren was receiving from the playgroup greatly outweighed the sense of loss I sometimes experienced.

In a way, the playgroup helped me to become more accepting of Lauren's differences. This was not easy. Initially, I would try to encourage Lauren to imi-



During the first meeting of the neighborhood playgroup, o participants (from left) Sam, Tracy and Lauren work on an art project.

tate the behavior. of the other children. I hoped—somehow—they would not notice she was "different." When Lauren went into "tantrum mode," throwing herself to the ground in front of the kids, I would think, "My God, they are going to notice!"

It took some time to let go of the tendency to try to make Lauren appear "like them," just as it took time for the other children to accept and understand her differences. It's funny—as I write this, I realize the kids were way ahead of me in this respect.

#### A sense of belonging

We continued to "play"—first on Fridays, then on Saturdays—for nearly



"Circle time" offered an opportunity for a variety of social activities including sign language lessons and discussions about disabilities. Participating in circle time during the first year of the playgroup were (from left) Sam, Kelli, Becky and Lauren.

four years. Three years after the playgroup began, we moved from the neighborhood, but many of the original participants remained involved with what I called our "playgroup," and what Lauren described as "the kids coming."

Lauren's participation in the playgroup provided her with a sense of belonging. Neighborhood children now greet her enthusiastically. Before the playgroup, these same children headed in the

opposite direction upon her approach. Lauren is now a welcome participant in most activities. Through our community's acceptance of our daughter, our entire family has developed that same sense of belonging.

As for me, I have thoroughly enjoyed my role in the lives of these neighborhood children. The playgroup has provided me with an opportunity to see my daughter in a situation that fosters success and belonging. Friendship is a dream we have for all our children; the playgroup became the tool for my "spe-



"Arts and crafts" activities lent themselves quite naturally to individualization. Different children could work on different activities during the same art session. And children with more advanced skills (like being able to use scissors) were able to help younger or less-skilled children.

cial" child to achieve that dream. As unnatural as it may seem, there are times when we have to *create* environments in which friendships can develop.

Lauren is now in a school setting that meets her academic and functional needs and makes a significant contribution to her social skills through inclusion opportunities. Her teacher shares my vision of the gifts our children can offer their peers without disabilities. Her belief in inclusion has rekindled my dream for Lauren's full inclusion.

Two years ago, I wrote in my journal: continued on page 46

#### Tips for Creating a Successful Playgroup

- Start with a small group. An initial group of no more than three, children, including your child, is a good beginning. If appropriate, you can invite additional children to participate at a later date.
- Explain your child's disability to other parents in as much detail as possible. Do not assume that they already understand your child's condition; even close friends may be cautious about asking questions. Once parents have some details, they become capable of answering questions their child may ask at home.
- Set a regular day and time to meet. This allows the parents of your participants to plan their schedules and increases the likelihood of regular attendance. It also gives you time to prepare for each session—both physically and mentally.
- Prepare a schedule of activities for each session. Having a schedule allows you and the children to have expectations and gives the day some definition. It will also come in handy when one of the children does not want to leave an activity; you can refer to the schedule and say, "Look, the schedule says it's tirne to do this now."
- Create opportunities for your child to shine. Perhaps your child has
  mastered a skill and can assist another child. This will provide other
  children with another view of your child's capabilities.
- Design activities in a way that allows everyone to experience success. For example, some children can practice writing their names, while others trace theirs or just practice holding a writing instrument.

- Incorporate your child's IEP goals into your program. A playgroup offers invaluable opportunities for your child to see his or her peers "model" desired behaviors. For example, your child may be working on her IEP goal of tracing a straight line while other childre are tracing letters, writing sentences or practicing cursive writing. The important thing is that all the kids are holding crayons, pens or pencils and writing on paper.
- Promote socialization by pairing children to work together, and by having one child assist another. When pairing children, be prepared to assist them with "cooperation skills."
- Keep notes, project samples, pictures and videotapes of the group. This helps you mozsure the progress of your group. Your child may enjoy watching the videotapes—Lauren does! You may also want to show them to parents of new children you would like to invite to your group.
- Take time off when needed. If you feel burned out for longer than
  a few hours after a playgroup session, you may need to examine
  your schedule and activities, or consider hiring a helper. Teens can
  often fill the helper role.
- Be kind to yourself. Developing a group takes time, effort and commitment on your part and the part of others. A playgroup evolves over time and through the development of relationships between you and the children. Think of yourself as the conductor of a new group of musicians; it takes time to create harmony in the symphony

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"Perhaps, in the near future, our children will remain where they belong—in their communities, developing natural bonds at neighborhood schools, in their front yards and at Girl Scout meetings; and their lives, along with the lives of their families, will be one of inclusion, not exclusion."

As parents, we can be the driving force to create this opportunity for our children. Through partnerships with friends, neighbors and spouses, a playgroup may be the start of community inclusion for your child. **EP** 

Trudy Grable lives in Saratoga, California with her husband, Martin, and children, Heather, 21, Nicole, 17, and Lauren, 10. Trudy is the director of technology resources at PHP—The Family Resource Center in Santa Clara,



Taking a break during a 1994 nature walk are (clockwise from left) fourthyear playgroup participants Jessica, Lauren, Rachel, Becky, Andrew and Elizabeth. The children used the "neat stuff" they collected during their walk to make a collage.

California, where she is also sysop (systems operator) for the LINCS BBS (electronic bulletin board; 408/727-7227, N-8-1, up to 14,400 bps). Her Internet e-mail address is trudy@php.com.

Trudy is the author of Where Do I Begin? Integrated Neighborhood Playgroups, a manual to assist parents in developing their own neighborhood playgroups. (See below for ordering information.) This article has been adapted from a portion of that manual.

#### Want to learn more?

Where Do I Begin? Integrated Neighborhood Playgroups by Trudy Marsh Grable is a practical, easy-to-read, 85-page manual for developing a neighborhood playgroup that will meet the individual needs of your

child and family. Included are suggestions for selecting participants, planning successful activities and handling questions and conflicts. To order, contact PHP—The Family Resource Center, 3041 Olcott St., Santa Claru, CA 95054-3222; (408) 727-5775; e-mail: inp@php.com. A \$15 donation is suggested (all proceeds benefit PHP's Family Emergency Fund).



With Trudy acting as the trainer, a playgroup training program is available within the state of California. These day-long works was have been developed through a small grant from the California State Department of Developmental Services. Contact PHP for more information.

639

### MEDIA

#### TAKING

Irene Pollin, author of TAKING CHARGE: OVERCOMING THE CHALLENGES OF LONG-TERM ILLNESS, is a parent and psychiatric social worker. In dealing with her children's illnesses, Pollin became aware that professionals receive scant training to help individuals and families cope with long-term effects of

chronic illness or disability. Neither mental health nor medical specialists provided the support she and her husband needed. After the loss of two of her own children, Pollin returned to school for training as a psychiatric social worker.

Although Taking Charge: Overcoming the Challenges of Long-Term Illness was written specifically for individuals with long-term illnesses, every chapter is filled with powerful information and helpful support for parents and other family members. Here's what nationally-syndicated columnist Ann Landers says about Taking Charge: "[This] book... should be required reading for everyone facing the challenge of long-term illness, whether their own or that of a loved one... It could be the most valuable gift you will ever give."

In Pollin's words—"I have discovered that by confronting and taking charge of your fears, you can learn to accept your [or your loved one's] long-term condition. Indeed, you can once again take charge of your life. This book will show you the way." TAKING CHARGE is available from Exceptional Parent Library (800/535-1910). The following is an excerpt:

#### Feelings You Might Want to Share

You may believe that your family cannot understand you because they're not sick. I have found, however, that although they can't identify with you completely, they can be supportive if you let them know what you're thinking. You might want to share the following emotions and needs with your family to spur open communication:

- Tell them that you don't expect them to solve your problems. You just need them to listen and be supportive.
- Tell them that you feel like a burden on them and need reassurance that they don't mind giving the extra attention you require.
- Tell them that you know they sometimes feel trapped by the illness and by you.
- Tell them that you have thought a lot about it and often feel the same way they do; you are all victims of your disease and the position it has put you in.
- Describe to them the kinds of support you need

- from them. If you want space and time alone, ask for it. If you need them to be around more, ask for that too. (This may not always work perfectly but it's better than not expressing your desires.)
- Let them know that you miss going places (like sporting events or concerts) with them that have become difficult for you to manage. Help them find alternative activities you can all enjoy or if you are too incapacitated to attend an event, encourage them to go with someone else.
- Tell them that you understand that they're not angry at you, but at the situation, so they need not feel guilty.
- Reassure them that you understand their feelings—they aren't too different from yours. You're in this together.
- Guide them on how to treat you: with sympathy, empathy, or support while honoring your independence and your feelings.
- Let them know how important they are to you.
   You need them and you need to be needed.
- Tell them how much you appreciate all that they're doing for you, even if they can't meet your expectations. (In fact, given the circumstances, you might have to reevaluate those expectations.)
- Ask how they feel about talking about your illness; do they fear being hurtful towards you?
   What subjects does it hurt them to bring up and what ones are all right to bring up? (Be sensitive about how much they can tolerate.)
- Ask if you're being unreasonably demanding. Back off if you are!
- Ask if they need time off. If they do, tell them that you understand their needs and want them to have respite.

Watch for the danger signs of burnout, such as withdrawal and short tempers or anger directed at you. You can suggest family counseling if you feel that tension is building and you don't know how to handle it. A minister or rabbi, hot-line volunteer, self-help group, good friend, or professional counselor can help in times of difficulty.

Reprinted with permission of Times Books, a division of Random House, Inc., from TAKING CHARGE, © 1994 by Irene Pollin.

CORRECTION: The excerpt from TAKING CHARGE, that was published in the June 1995 issue, featured a picture of a different book with the same title. EXCEPTIONAL PARENT regrets the error.



## Why Parents and Children with Disabilities Should Have the Right to Use Facilitated Communication

by Douglas Biklen

n the mid 1970's, Australian educator Rosemary Crossley rediscovered a method of communication that American teacher and parent Rosalind Oppenheim had used as early as the late 1950s and had written about in her 1974 book *Teaching Methods for Autistic Children*. The technique, which Crossley named facilitated communication (FC), involved providing physical and emotional support to a person with a developmental disability (such as autism, cerebral palsy and Down syndrome) and limited

or no speech. This support enabled the person to point reliably, and thus to communicate by pointing at pictures, at whole words or at letters to form words. Crossley first used FC with Anne McDonald, a girl with cerebral palsy living in an institution for children with multiple disabilities, all of whom were presumed severely retarded.

The method is intended to help individuals overcome problems of voluntary physical movement including finger isolation (for example, the ability to extend the index finger while keeping the other fingers folded under the palm), tremor, hand-

eye coordination and initiation of action (the ability to begin, continue and stop a movement).

#### Controversy over authorship

Controversy over the method has to do with whether facilitated messages are authored by the person with the communication impairment or by the facilitator.

Anne McDonald proved her communicative competence to the satisfaction of the Victorian Supreme Court by typing "string" and "quit," after the words "string" and "quince" were given to her by the presiding officer while her facilitator, Crossley, was out of the room. A court-appointed psychologist also had Anne take a Peabody Picture Vocabulary Test, in which she selected from a set of four pictures the one that illustrated the meaning of the word said by the examiner. She was able to accomplish this task independently, that is, without physical support. Her score on the test was within the range expected for a person her age. McDonald has since completed a Bachylor's degree and is currently enrolled in a Master of Arts degree program.

However, the first formal, published FC validation study (a study to determine whether FC is valid communication) produced results that left many observers in a quandary. In this study, done by the Victorian state [Australia] government, three FC users were asked to describe gifts their facilitators had not seen; three others were asked to reply to questions different than those given the facilitators. Although the study showed that the method worked for some people, it also revealed evi-

dence of facilitator influence on communication.

#### Studies raise skepticism

Criticism of FC has been harsh, fueled by the results of numerous controlled studies in which people using FC have failed to validate their communication. In the first, conducted in 1992, 12 individuals classified as autistic were shown colored pictures of familiar objects and asked to name them. *None* of the individuals gave correct responses when shown items different than those shown to the facilitators. However, in two instances, individuals did

name appropriate categories for the items they were asked to identify—responding "vehicle" instead of "van," and "food" instead of "bread."

Numerous subsequent studies seemed only to confirm these results. In one study after another, individuals were shown pictures that their facilitators could not see, or were asked questions that their facilitators could not hear, and they did not respond correctly.



It did not surprise me that people did so poorly on the early tests. Being observed or tested may cause individuals to perform more poorly than usual. Moreover, none of the early studies gave participants the chance to practice test-taking. In each case the tests were done in one or two sessions.

Several recent studies, however, *have* revealed authorship by people using FC, although at the same time noting the presence of facilitator influence. Dr. Carol Vazquez conducted a study in which one individual was able to describe a video his facilitator had not seen and another was able to identify



Lucy Harrison, 18, uses a typewriter while her mother, Nita, facilitates with one hand on Lucy's shoulder. Lucy began using FC in 1990, and was initially facilitated with wrist-level support.

objects that her facilitator could not see. Vazquez concluded, "...erratic in their performance, each subject was able to report information unknown to the facilitator in one out of four controlled sessions."

Elliot Simon and his colleagues asked FC users to report on activities in which they had engaged-such as getting snacks from a vending machine and visiting the library. The researchers found that "for some students there is evidence of authorship for information unknown by the facilitator." But the researchers also determined that facilitators could influence individuals' communication. In light of these findings, these researchers strongly advised pursuing the goal of independent typing, a goal I had also advised in my book, Communication Unbound

In a 1993 study, Ogletree and his colleagues evaluated a fourand-a-half-year-old's communication abilities. Without FC, the child was judged to have the communication ability of a sixmonth-old. With FC, he produced words-often misspelled or speiled the way they sounded-and described activities about which his facilitator was kept unaware—for example, blowing bubbles, playing with water and swinging. In conclusion, these researchers called for "an open but objective posture regarding the method's use with persons with autism."

A year-long government study in Queensland, Australia, published in 1993, found that 87 percent of the 24 clients evaluated were able to validate their communication through responses to questions about their activities—for example, asking a person to report on a gift received while the facilitator was not present or to report on piano playing about which the facilitator was unaware. About half of these individuals were also successful in answering multiple-choice tests in which the facilitator did not know the answers (such as names of family members).

The largest study of FC to date has been carried out in the California public schools by Donald Cardinal and his colleagues. Their unpublished study (currently under review by a professional journal) included more than 3,800 trials, more than all of the above-mentioned studies combined. Students classified as "severely disabled" were asked to spell randomly-selected words that they were shown while the facilitator was out of the room. They were asked to spell five words per session, in three sessions per week. By the end of the six-week study, 74 percent of the students were able to correctly spell one or more of the words

shown to them by the tester while the facilitator was out of the room; half were able to spell at least two of the five words. On average, students reached their peak performance at this task after nine sessions. The re-searchers concluded that their test validated communication when many others had failed because the length of the study allowed students to practice the test activity though not the actual words—and because the activity occurred under natural conditions, as part of the regular school day. For each word typed, researchers estimated that there was no more than a one-in-one-hundred chance that the facilitator could guess the word correctly.

At Syracuse University, we have two controlled research studies underway in which FC users are

proving their communicative competence. Both studies show that people are often able to succeed with validation tests if they have opportunities to practice the type of test activity and if the task accommodates particular difficulties such as word retrieval.

Nearly everyone has difficulty with word retrieval—for example, when we cannot think of the name of someone we see during the day, even though we may typically be able to recall the correct name some time later. Many people who use FC seem to have extreme word retrieval difficulty, even for naming obvious objects. In testing, one strategy to avoid word rerieval problems is to provide multiple-choice answers; this allows the correct answer to be available for selection.

In our current studies, individuals have taken several sessions-in some cases, as many as eight sessions-before succeeding with validation tasks. Nearly all of these tasks include multiple-choice options or other tasks that do not involve word retrieval-for example, unscrambling letters to form a word or completing math problems.

In light of these studies, reasonable people must admit that some individuals who were previously believed incapable of literate communication have demonstrated that under the right conditions, they are able to convey their own thoughts via FC.

Independent typing

The goal of FC is independent typing. Many people using FC may be able to reach that goal. Rosemary Crossley and her colleague, speech pathologist Jane Remington-Gurney, report that more than 30 individuals with whom they had worked in Australia are now typing independently. In North America, there have also been reports of substantial progress in typing ability, including independent typing.

At the 1994 annual conference of TASH (The Association for Persons with Severe Handicaps), I presented videotapes of two individuals typing without any physical support; each had first learned to communicate with facilitation. Both were previously believed to be severely retarded, but have since demonstrated excellent literacy skills.

Again, reasonable people must admit that individuals who learn to communicate with facilitation and then achieve independent typing have demonstrated the ability to communicate their own ideas.

continued on page 50

#### To learn more...

- Communication Unbound, by Douglas Biklen, focuses on how FC works, the controversy, ways of confirming authorship and implications for understanding disability and ability. Published by Teachers College Press, Columbia University (PO Box 2032, Colchester, VT 05449, 800/488-2665; \$17.95 plus \$2.50 handling).
- Under Controlled Conditions: Validating Facilitated Communication (video, 23 min.) documents a study in which people using FC learned to validate their communication while playing computer games. Every Step of the Way: Toward Independent Communication (video, 20 min.) shows how individuals using FC have begun to achieve independent typing. Available from the Facilitated Communication Institute, Syracuse University, Syracuse, NY 13244 (\$50 plus \$2.50 handling).
- I Don't Want to be Inside Me Anymore: Messages From an Autistic Mind, by Birger Sellin, is an autobiographical account of autism, written through FC. The book was written by a teenager in Germany, where it sold more than 50,000 copies: The English translation was published by Basic Books in 1995 (\$22, may be ordered through local bookstores).



#### Allegations of abuse

There have been concerns about allegations of abuse made through FC. The only scientific investigation of this issue was conducted by pediatrician Ann Botash and her clinical team at a Syracuse, New York hospital. When any child makes an allegation of abuse, a hospital team examines the case to see if there is any other "indication"—other than the allegation—to suggest that abuse might have occurred. Other "indications" of abuse might include physical evidence, a confession by the person accused or confirmed abuse of other children in the family. Botash's team examined all abuse allegations made through FC that were evaluated at the hospital over a three-year period, a total of 13 cases. The study found that other "indications" of abuse were found in 47 percent of these cases, the same percentage as in cases where allegations were not made through FC.

In addition, two recent court cases have upheld the right of an individual to use FC in court proceedings. In one case, a coworker of the accused said that the defendant had admitted his guilt during a private conversation outside of court.

In any instance of alleged abuse made through FC, there must be extreme care to assure that the FC user is the author of the allegation. I have consistently recommended a simple procedure—bring in a second facilitator who is unaware of the first allegation to see if the person can repeat his or her statement.

#### Ethical concerns

Given these findings, I strongly endorse the position taken by TASH: that no parent or person with a disability should be denied the right to use the method of communication of his or her choice, that no person should be denied access to basic rights—including the right to appear in court—on the basis of his or her communication method, and that validation of communication ability should always be discussed with the person who uses FC and should include multiple strategies attempted over long periods of time.

The latest research evidence on FC and the achievements of individuals using FC require us to ensure its future availability. It is not a miracle and it certainly will not work for everyone, but those who might benefit from it deserve the

right to learn to use it, to type out their words, to be heard, to prove their communicative competence and to be recognized for their accomplishments. EP

Douglas Biklen, Ph.D., is professor of cultural foundations of education and director of the Facilitated Communication Institute at Syracuse University, Syracuse, New York.



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### Connections



The Newsletter of the National Center for Youth with Disabilities

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Alison Mann Rinehart lives in a house in St. Paul, Minnesota, with three friends—Mindy, Damon and Tyler. They make their own breakfast, and with some help from a deaf woman who lives with the kids and is responsible for their



overnight care, Ali and Mindy take the public school bus to Humboldt High School. Tyler gets ready for Metro Mobility to transport him to and from work in nearby Roseville. Damon heads out to work in St. Paul.

Just finding school programs and jobs (not to mention housing and care) for four deaf youth who have mental retardation and other disabilities took the collaboration of many agencies and scores of people.

Reginald Redding, then Assistant
Superintendent for
Curriculum and
Instruction, MSAD, and
Alison's parents, Peggy
Mann and Gerald D.
Rinehart, convened a
meeting with
representatives from
numerous agencies,
including the:

- State Department of Education:
- St. Paul School District;
- Minnesota State Academy for the Deaf (MSAD);

- State Department of Human Services (including the Deaf and Hard-of-Hearing and Developmental Disabilities Divisions);
- Division of Rehabilitation Services, Ramsey County Human Services; and
- Institute on Community Integration (the University of Minnesota's UAP).

They met for the first time just two years ago. "Unfortunately, there are no long-term programs in this state that serve deaf young adults with mental retardation. [We] wish to form a coalition in order to improve service options. Our goal for this first meeting will be to determine if there is a need and to identify various strategies to develop an independent living program for deaf or hard-of-hearing young adults with mental retardation," Redding wrote to the participants.

> Collaboration Turn to page **52**



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From time to time, the National Center for Youth with Disabilities highlights innovative projects that enhance the ability of adolescents and young adults to grow, develop, work and participate in community life to their fullest capacities. And while the story about the I.F. Best Group Home does that, it proved to be very difficult to write. You see, Alison is my daughter and this project is as emotionally charged as any milestone in our family; a college graduation, a marriage, the birth of a child.

We couldn't imagine Alison's future a mere 10 years ago. She was deaf. She had mental retardation. Some days she could walk without help, other days she needed to use a wheelchair. And some days she could barely stay awake. There were times when her hand or arm or mouth twitched uncontrollably, sometimes for days on end. She required multiple medications daily to be in precarious balance to protect her from seizures. She was fragile. A virus could keep her home from school for a week or compromise her enough to require hospitalization. She had no understanding of danger. It's awfully hard to imagine a future when all your energy is used to manage a child's problems and disabilities.

Alison's future began to take shape when we started asking the same questions we ask about all our children. What will she do? Where will she live? How will she find a meaningful place in her community? Who will be her friends? Where will she go to church? Where will she hang out? Alison's future began to take shape as we began to trust others to help us.

When a neighbor's home became a group home, I thought maybe Ali could just grow up and live nearby. Slowly, I could imagine a time when I would do what every other mom does with grown children. Take my daughter to lunch. Shop. I could imagine Ali visiting on birthdays and holidays, or stopping by on a Sunday afternoon, unannounced. I could imagine running into my daughter in the store or at the Y.

What we as a family and NCYD as a program have learned is that it is critical for families and youth to think about the future. The dreams we have for our children, and the dreams they have for themselves, will change and grow over time. And, kids and parents won't always agree.

These days, when Alison comes to her our house, she's delighted to eat my cooking, happy to see her younger brother, and she always asks about her older sister. But after a couple of hours, Alison will put on her coat and announce, "My house now." At 19, Alison still has all the same disabilities she had 10 years ago.

**PMR** 

#### Collaboration From page 51

While a number of the agencies involved had identified a need to increase the availability of communication accessible services for these youth, not much had moved ahead. A number of agencies even had interagency agreements in place, but they needed a catalyst, someone with a vision. "That's what the Rineharts provided. Having parents advocate for programming added immediacy to goals and objectives written by the Deaf Services (DSD) and Developmental Disabilities Divisions of the Minnesota Department of Human Services," JoLynn Blaesar, Planner, DSD, says.

This ad hoc coalition spent a year discussing how they might design, develop, fund, and evaluate a pilot transition program for up to 12 deaf youth that bridges all the agencies. The biggest difficulty? Identifying a site. Time and time again the team realized that youth with disabilities—especially in the area of communication-need to develop community living, job, recreation and independent living skills right in the communities where they will live. It just didn't make much sense to develop resources in one community when the youth would eventually move to another.

This notion might have stymied the work of the coalition if they had limited their understanding of community to geography. But at the same time, a deaf service provider was knocking at the county's door, wanting to provide group home services for deaf youth. Steven Hogenmiller and his wife, Monica, had both worked in group homes, sometimes with deaf people. They saw the frustration that limited communication added to their clients lives. Their goal was to start a service provision company, Laurant Clerc Services, Inc., to provide skilled care and programming in American Sign Language for deaf youth with developmental disabilities." Our goal is to create an environment for language development, communication and socialization improvement using community resources to build self-esteem and confidence," Hogenmiller explained.

#### **DHS & County Social** Services Combined Strenaths

From that point on, natural work groups developed. County social workers made application for special waivers. Thirteen months after the first meeting, four youth from three counties who had

> Collaboration Turn to page 53

Collaboration From page **52** 

attended the Minnesota State Academy for the Deaf were offered the opportunity to move to St. Paul, Minnesota, and receive their services as part of the Deaf community.

State and county human services developed a strategy to assist the Hogenmillers to become county providers of adult foster care. The mountain of reports, license application and paperwork involved in becoming county approved providers is daunting enough when English is your primary language. The county had never worked with a deaf provider before. But with technical assistance from both the Developmental **Disability Services** Division in the county and Deaf Services Division of State Human Services and the Hogenmillers' dogged persistence, the paperwork was

#### Contact:

Peggy Mann Rinehart NCYD Box 721 UMHC 420 Delaware St. S.E. Minneapolis, MN 55455

or Steven Hogenmiller. Executive Director Laurant Clerc Services, Inc. 1242 Eustis St. St. Paul, MN 55108



completed by October 1—the day the home opened.

### Creativity Stretches School Programs

In Minnesota, as in most states, children with dual disabilities have a tough time fitting into school. When Alison was placed with just deaf kids, she could understand the language but she couldn't manage the curriculum. When placed with peers who have mental retardation, she might be able to manage the curriculum, she just couldn't communicate with anyone. St. Paul school administrators and teachers struggled to make their strong community-based, independent living programming accessible to deaf children without breaking the bank. Part of the solution was to hire deaf adults and interpreters as job coaches and educational assistants. A greater part of the solution has been deliberately enhancing communication between programs and among program administrators.

Indeed, while interagency policy level administrators and planners were steering this sometimes unwieldy project, a second team of teachers and social workers, school nurses, aides, and *especially* Alison and her friends, were developing their own plan. Mo Fahnestock led the group in planning a meaningful and fulfilling life.

#### Still Growing

Collaborative projects built on mutual strengths take on a life of their own. They keep growing in depth and meaning as the community nurtures them. Alison, Mindy and Damon transferred to Humboldt High School in October; Damon is already working full-time in the community like his housemate,

Tyler. Alison and Mindy will move to community sites this summer.

The Hogenmillers' company is thriving. They've provided employment for many skilled deaf people, and slowly these four youth are becoming members of the deaf community.

Nothing worth doing goes ahead without problems. Ali made an unnecessary emergency trip to the hospital one weekend. Mindy fell in school and chipped a tooth. The dishwasher needed to be replaced; the water heater wasn't big enough. And, Damon really did need a television of his own. Phyllis, the first "live-in" staff, was promoted, moved out, and El moved in.

But through it all, the kids are persevering, growing and, most important, learning how to become independent and finding their place in the neighborhood and in the community.



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#### Getting Youth Serving Agencies Together:

#### Where Do We Go From Here?

The publication,
Together We Can: A
Guide for Crafting a Pro
Family System of
Education and Human
Services, outlines a fivestage process for
building a new system.
While this publication
looks to the really big
picture, "to create a pro
family system of
integrated services to
address the complicated

problems children and families face in today's society," the stages identified can provide a road map for families and youth as they plan their futures.

Stage 1: Gather the right people and commit to collaborate.

Communicate.

Stage 2: Identify a shared vision and goals that you can talk about in concrete

language. Communicate.

Stage 3: Develop a strategic plan that defines exactly what you want to accomplish, who will do it and how. Communicate.

**Stage 4:** Take action. Communicate.

Stage 5: Adapt and expand the original plan as necessary.

Communicate.



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#### For More Information:

#### **Connect With The National Resource Library**

The National
Resource Library brings
together comprehensive
sources of information
related to adolescents,
disability and transition
to meet the needs of
professionals who work
with youth with
disabilities as well as

their parents and others invested in their success. The database contains five files:

- Bibliography
- Programs
- Training Materials
- Technical Assistance
- Health Care Reform

Entry points to the Library's files are through the language and issues of individual fields. Information in the files is interdisciplinary, offering the many views that may enhance practice with adolescents and young adults with disabilities.

The National Center for Youth with Disabilities is a program of the Society for Adolescent Medicine and the Adolescent Health Programs at the University of Minnesota. Publication of Connections is supported, in part, by project MCJ-275045 from the Maternal & Child Health program (Title V, Social Security Act), Health Resources & Services Administration, Department of Health & Human Services.

The Center's mission is to improve the health and social functioning of youth with disabilities through providing technical assistance and consultation, disseminating information, and increasing the coordination of services between the health care system and others. Center activities are directed at enabling youth to become full participants in their communities.

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## HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

#### **Self-Funded Insurance Plans**

My three-year-old son has autism. Our health insurance coverage is with a self-funded plan that is refusing to cover his medical expenses related to his autism. The plan does not cover treatment of "mental-nervous disorders," and this is how they have classified autism.

I have filed an appeal, pointing out that autism is a developmental disorder, not a psychiatric condition. Several of my son's doctors have written letters of support also. However, the appeal has been denied. Do you have any suggestions?

L.O., New York

A variety of health insurance programs are available in the United States. There are traditional plans, managed-care plans, government-sponsored programs (including Medicare, Medicaid and a variety of state plans), self-funded plans and other, unique programs.

Each represents a different approach to health insurance, and each is regulated somewhat differently. Traditional health insurance plans, for instance, usually involve an agreement between an insurance company and an individual consumer. That agreement deals with issues such as the specific benefits that will be offered.

Traditional plans are usually regulated by the state in which the policy was issued. Government-sponsored plans are regulated by a specific state or federal agency, with benefits established by law and government regulation.

#### Self-funded plans

Although many people are more familiar with traditional health insurance plans, self-funded plans play an important role in the health insurance structure. In fact, more than 60 percent of Americans who have health insurance coverage through their employers are covered under self-funded plans.

Self-funded plans are typically established through an employer or union—the "plan sponsor"—rather

than through an insurance company or government agency. The plan sponsor usually pays claims cirectly. Although an insurance company may be involved, it acts as a "third-party administrator," not as the insurer.

Therefore, in a self-funded plan, the insurance relationship is usually between an employee and his or her employer, not between a consumer and an insurance company or between a consumer and a government agency. Most self-funded plans are regulated under a federal law called ERISA—the Employee Retirement Income Security Act—not under state law.

#### The importance of regulation

The question of how a health insurance plan is regulated can be extremely important. Over the past few years, there have been a number of cases dealing with the ways self-funded plans have either limited benefits or class-ified medical conditions. Those cases have involved such conditions as Alzheimer's disease, cancer and AIDS.

Of course, all types of health insurance programs may exclude or limit coverage for specific services. Over the past few years, however, several states have issued new regulations mandating standardized health insurance plans that include a number of important consumer protections. But those regulations usually do not apply to self-funded plans.

#### The next step

Regardless of the type of insurance plan involved, the first step in a situation like yours is to go through appropriate appeal procedures. You've already completed that step, apparently without success.

Often, the second step would involve an appeal to your state insurance department. However, since your case involves a self-funded plan regulated under ERISA, the state insurance department probably cannot help.

However, there may be a number of

legal issues involved in this case, including your rights under ERISA and under the Americans With Disabilities Act (ADA). Thus, I think your next step may be to consult an attorney who specializes in insurance or disability law. In your area, the Disability Law Center (c/o New York Lawyers for the Public Interest, 30 W. 21 St., 9th Fl., New York, NY 10010; 212/727-2270, voice; 212/727-2997, TTY) has an interest in helping people with such issues. [EDITOR'S NOTE: In other areas, contact the National Legal Aid and Defense Association (1625 K St., NW, Ste. 800, Washington, DC 20006; 202/452-0620, voice; 202/872-1031, fax) for referrals to local resources.]

You should also consider writing to federal legislators about this issue. Congress is beginning to discuss health insurance again. One topic that is likely to come up is the possibility of changing the ERISA law to bring self-funded health insurance plans under at least partial state regulation. Your experiences may help legislators better understand the situation as it relates to children with disabilities.

However, remember that companies are not obligated to offer health insurance coverage. Self-funded plans cost significantly less than traditional plans; according to the Self-Insurance Institute of America, many companies might not be able to offer *any* health insurance coverage if self-funded plans were not available. **EP** 

In this column,
Richard Epstein
answers readers' questions about health
insurance. Send your
questions to him at
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If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.



# ASK THE DOCTOR

by David Hirsch, M.D.

# The Ketogenic Diet

Our four-year-old son has developmental delays and a very severe form of epilepsy. His seizures have been diagnosed as being myoclonic in form (rapid jerks of flexor muscles). Sometimes he seems to have staring spells which are seizures also. He has been on many different anticonvulsants-up to three at a time-but with minimal improvement in his seizures. My husband and I feel that the medications are making him very lethargic; he sleeps most of the day. We are strongly considering trying the "ketogenic diet" that we have heard about recently. Does this seem reasonable?

A ketogenic diet for the control of seizures is a treatment for epilepsy that has been in use for many years—alone, or sometimes in conjunction with anticonvulsive medications (medications to control seizures). Although there are a few theories, nobody really knows why the diet reduces or stops seizures in certain children.

The ketogenic diet consists of foods that cause the body to produce ketones, primarily a byproduct of fat metabolism. A person on a well-balanced diet consisting of carbohydrates, protein and fats will derive energy primarily from the metabolism of glucose—metabolism being the process whereby food is converted to energy. In contrast, a person on a ketogenic diet derives energy from "burning" fat, rather than glucose.

A ketogenic diet consists of foods such as heavy cream, butter, other fats and only a limited amount of protein. Essentially no carbohydrates (sugar and starch) are allowed. Protein and calorie intake must be set at levels that meet requirements for growth. Vitamin supplements must also be used appropriately.

The ketogenic diet may sound much easier to do than it really is. It should never be attempted without very close medical and dietary supervision. Typically, the diet is started in a hospital setting after several days of severe caloric restriction. This initial restriction of food intake causes the body to begin "burning" fat for energy, starting the production of ketones. During this initial hospitalization, a dietitian works with the family and child to set guidelines for the types and amounts of food the child may have. Once started, and barring any major complications, it is essential that the patient follow the diet strictly. "Cheating"—whether accidental or intentional-may result in increasing or restarting seizures.

According to studies done at Johns Hopkins Pediatric Epilepsy Center, the optimal age for the diet is between one and eight years. Younger children are more prone to hypoglycemia (low blood sugar) when on the diet and older children who are oral feeders (as opposed to tube feeders) are more resistant to following the ketogenic diet, primarily because of its limited taste appeal.

The ketogenic diet should be considered another therapeutic option, just as the option to use or change anticonvulsant medications. This diet should not be the first choice among options for seizure control, but it is a viable treatment for children with many types of seizures that are not well controlled with anticonvulsants or where anticonvulsants cause significant side effects.

Just as with drugs, the ketogenic diet has potential side effects including hunger, thirst (because of the decrease in fluids taken in as part of the diet), constipation (because of the small volume of food and high concentration of fat in the diet), hypoglycemia, kidney stones (because of too little liquid),

hypocalcemia (low blood calcium), hyperuricemia (excessive uric acid in the blood) and acidosis (a build-up of acid in the blood). Also, if a child continues taking anticonvulsant medication, the ketogenic diet may make him more prone to a buildup of the medication in the body because the diet may change the way the body absorbs the medication, the way medication adheres to proteins in the body or the way the brain metabolizes the medication. As mentioned above, the diet must be rigorously adhered to and closely monitored. Even slight amounts of excest carbohydrate may precipitate a seizure in susceptible individuals.

Johns Hopkins has reported that the ketogenic diet appears to be very effective and typically well-accepted by patients and families. Of children with the most intractable epilepsy (the hardest to control), Johns Hopkins reports improved seizure control in 67 percent. Many of these children were able to reduce their anticonvulsant medications significantly; some were able to stop the medications entirely. Speaking from personal experience, I have had

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In this column, David
Hirsch, M.D., a pediatrician and member of the
Excernolial Paneri's
Editorial Advisory Brand,
answers questions from
readers. Dr. Hirsch is a
partner in Phoenia
Pediatrics, Ltd. in
Phoenit, Arizona. He spe-

ciolizes in treating children with developmental disabilities and obrente illnesses. Since Dr. Hiroch is responding to letters and has not examined the child in question, parents need to review his suggestions with appropriate professionals. Dr. Hiroch mentions specific products or medications only to illustrips suggestions; he is not indorsing any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brooklins, MA 02146 5005, (617) 730 5742 (Flat).





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Circle #11

# ASK THE DOCTOR

continued from page 56

two patients recently who have had significant improvement in seizure control and quality of life on the ketogenic diet. One is no longer on anti-epileptic medications.

I believe there may be a role for the ketogenic diet for your son. Again, the ketogenic diet—like the use of any medication—is a serious undertaking and must be done under the close supervision of your son's pediatrician and pediatric neurologist and by a dietitian who is experienced with the diet.

For more information, you may want to investigate the following resources:

- The Epilepsy Diet Treatment: An Introduction to the Ketogenic Diet (paperback, 1994, 180 pp.): Written by medical professionals at Johns Hopkins; Demos Publications, 386 Park Ave. S., Ste. 201, New York, NY 10016; (800) 532-8663; \$21.95.
- An Introduction to the Ketogenic Diet: A Treatment for Pediatric Epilepsy (video, 45 min.): The Charlie Foundation, 1223 Wilshire Blvd., Box 815, Santa Monica, CA 90403; free (send card with name and address).
- The Johns Hopkins Ketogenic Diet Fact Sheet (fact-sheet, 4 pp.): The Epilepsy Foundation of America, 4351 Garden City Dr., Landover, MD 20785-2267, (800) 332-1000; free.



Circle #44



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Circle	Advertiser
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118	AOUATIC THERAPY
173	BETHESDA LUTHERAN HOME
113,112	BRAUN CORPORATION
25	CHARLES C THOMAS
11	CHILOREN'S SPECIALIZED HOSPITAL57
180	CLARKE HEALTHCARE PRODUCTS, INC58
150	COLUMBIA MEDICAL
126,208,209,210	CONVAID
74	CUMBERLAND HOSPITAL21
107	DEVEREUX FOUNDATION18
105	DIESTCO MANUFACTURING 58
	EPILEPSY FOUNDATION OF AMERICA38
123	EOUIPMENT SHOP
	EXPOCON MANAGEMENT ASSOC., INC
156	EXPRESS MEDICAL SUPPLY 63
135	FORD
44	HARD MANUFACTURING
166	HAVERICH ORTHO SPORT
14	HDIS
3	HEARTSPRING
77	HMS SCHOOL42
101	HOMECARE PRODUCTS11
110	#NNOVATIVE PRODUCTS
26	JA PRESTON
	KALEIDOSCOPE
· 98	KID-KART/KID CARE 15
45	LAUREATE LEARNING 22,23
131	MARYLAND INSURANCE GROUP
161	PATHFINDER VILLAGE 46
12	PLUM ENTERPRISES42
22	PRINCIPLE BUSINESS ENTERPRISES, INC
80	R.J. COOPER & ASSOC 40
63	RACING STROLLERS34
41	RIFTON, INC
33	VAIL PRODUCTS
247	VIEWPOINT MANUFACTURING, INC 14
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(800) 562-1973 Customer Service, U.S. only. For international customer service, call 201-489-0871

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July 1995

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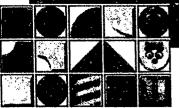
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# NEW PRODUCTS

## **BLOCKS IN MOTION**

Unlike traditional computer paint programs, which require

fine motor skills to perform a series of complex steps, Blocks in Motion allows a child to select a shape from a palette of shapes, click on it, point the mouse to the position on the background where the shape is to be placed, and click again to drop the shape into place. By joining a series of shapes similar to building blocks, children can create whole pictures. Requires a Macintosh computer with System 7.0 or higher, color monitor, three megabytes hard drive space, two megabytes RAM and a mouse.

Don Johnston, Inc., Wauconda, IL 60084-0639

Circle # 195

#### **ACTION VOICE**

This portable communication device allows children to communicate using pre-recorded messages. The one-minute model allows 10 messages to be recorded. The two-minute model features an 18-message recording capacity, enhanced volume and auditory scanning. Both models allow two adapted appliances, toys or other



devices to be controlled by any of the recorded messages. The Action Voice supports scanning, switch input or keypad overlays.

Ability Research, Inc., Minnetonka, MN 55345-0121 Circle # 196

## THE ARROW WALKER

The Arrow Walker is an adjustable walker designed to provide children with hands-free independent mobility in an



upright position. This walker features an arrow-maped chassis for stability and easier access through doorways and around obstacles. Directional locking casters allow the user to walk a planned course. A choice of three sizes (tiny, small and medium) and positioning accessories allow for customization.

Triaid, Inc., Cumberland, MD 21502 Circle # 197

#### **VOCAL ASSISTANT**

This augmentative communication device allows 16 messages to be recorded in any voice and in any language. All messages are available for playback at the touch of a single key. The first six messages may be of extended length,



allowing addresses, phone numbers and complex sentences to be recorded. Optional accessories include a remote speaker, keyguard and telephone interface.

GMIR Labs, Sunnyvale, CA 94087

Circle # 198

#### THE ADJUSTABLE

This height-adjustable table can be adjusted from a height of 25 to 50 inches with a minimum of effort. The adjusting mechanism consists of two cylinders controlled by hand levers on either side of the table. The levers are depressed to adjust the table, and released to lock it into position. A single-lever, one-handed adjustment lever is available. Additional cylinders may be added to

Northport, Inc., Excelsior, MN 55331

5 to 40 degrees is also available.

reduce the amount of effort required to

adjust the table with heavier loads. An

Circle # 199

adjustable-angle table top with settings from



# ×

# **PURE FLITE GEAR BAGS**

Pure Flite Gear Bags are gear bags designed for active kids and teenagers with physical disabilities. The design of the bags allows access to belongings without having to set aside crutches or reach around to the rear of a wheelchair. The student model, worn over the shoulders against the chest, features a large zippered top pocket to carry legal-size

notebooks, books and folders. A smaller easy-access pocket holds keys and wallets.

Pure Flite Gear, Pompano Beach, FL 33064

Circle # 200

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on Exceptional Parent's "Free Product & Information Card." Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).



# WHAT'S HAPPENING

# Video and Monograph Focus on the Power of Friendship

The Texas Planning Council for Developmental Disabilities has produced a 16minute, open-captioned video, Just Friends, and a 42-page collection of stories, Community Connections: Weaving Friendships.

Both highlight the experiences of teenagers and adults who participated in the Council's "Community Connections" projects. The projects, developed in seven areas across the state and intended to promote community inclusion, matched individuals with and without disabilities.

For a free copy of the video and/or monograph, contact Nancy Arms, Texas Planning Council for Developmental Disabilities, 4900 North Lamar Blvd., Austin, TX 78751-2399; (512) 483-4080 or (800) 262-0334 (TX only). A limited quantity is available; one copy of video and monograph per person or organization.



Connections focuses on the friendship between (from left) Brandy Pulliam. Amanda Iseli and Ginny Stander, all of Luiobock, Texas. Brandy has lived in a nursing home since the age of 13, when she lapsed into a three-month coma following a seizure. After regaining consciousness, she could no longer walk or talk. When asked how she and Amanda

communicate with Brandy, Ginny replies, "Oh, that's no problem. Brandy talks with her eyes." And what's the main topic of conversation when this threesome gets together? "Oh... you know... guys."

One of the 15 stories in Community

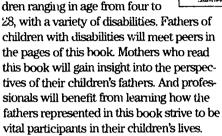
CHILDREN'S CARE HOSPITAL & SCHOOL (formerly Crippled Children's Hospital & School) is a private, nonprofit facility serving over 1000 children and families each year. Individualized, family-centered programs available through day

dence. Pediatric rehabilitation program now offered.

Contact: Nathan Anderson Children's Care Hospital & School 2501 West 26th Street

school, outpatient, outreach, or resi-

Sioux Falls, SD 57105-2498 (605) 336-1840 or (800) 584-9294 **Uncommon Fathers:** Reflections on Raisina a Child with a Disability is a collection of essays written by fathers of children with disabilities. These diverse dads have chil-



Uncommon Fathers, edited by Donald J. Meyer and published by Woodbine House, is available through Exceptional Parent Library, (800) 535-1910. 206 pp; \$14.95 (paperback).

# Young Musicians Competition

Very Special Arts, an international organization providing creative opportunities in the arts for children and young adults with disabilities, is accepting entries for the 1996 Panasonic Young Soloists Award. Any

instrumentalist or vocalist with a disability, younger than 25 and interested in pursuing personal or professional studies in music may apply. Each entrant must submit a video or audio recording of their work, a letter of application and a 250-word autobiographical statement detailing why he or she should be selected for the award. A committee of music professionals and educators will award \$5,000 scholarships to one or two winners. Each winner will also have the opportunity to perform at the John F. Kennedy Center for the Performing Arts in Washington, DC.

To receive an information packet, contact Very Special Arts, Young Soloists Program, Education Office, The John F. Kennedy Center for the Performing Arts, Washington, DC 20566; (800) 933-8721, voice; (202) 737-0645, TTY. The deadline for entries is September 15, 1995.



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NMEDA member. Owned by person with disability.

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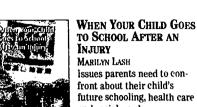
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# CRIENDSHIP

# CHILDREN'S PAGE

# "Bestest Buddies"

by Kristen Gain



By sitting on the back of the swing, Kristen has figured out a way to give both herself and Erin a wild ride at the same time.

y name is Kristen. I'm seven years old, and this is my story about my friend Erin Tatro.

Erin has cerebral palsy; her muscles don't work the same way as everybody else's. She kicks a lot and she moves her arms a lot. She giggles a lot, and she hums and grinds her teeth. She talks with a yes/no board with her hands and sometimes with her feet. She gets sick a lot, too.

I met Erin in kindergarten. At recess, I liked to push her in her chair.

Erin is in my first grade class, too. I like to help Erin if I finish my work early. I especially like to push her around on the field. She likes to be pushed on the bumpy part of the field. Sometimes, I get to ride Erin's bus home with her.

At Erin's house I like to swing, help Erin walk in her walker, do homework with her and sleep over. I like to ride in Erin's van and play her music tapes. On Saturday mornings, I like to go bowling with Erin and set up the bowling ramp so she can get strikes. We get good scores together. We're in Brownies together, too. And

we like to go to the movies, like the Lion King.

Me and Erin are bestest buddies. Best of all, when I tell Erin secrets, she doesn't tell anybody. **EP** 

Kristen Gain, 7, will soon be a second-grader at Pines Elementary School in Magalia, California. She lives with her parents, Tony and Nancy, brother Ryan, 12, and sister Kaylin, 9. Her hobbies include drawing, skating and riding her bike.

Kristen Gain helps "bestest buddy"

Erin Tatro smile for the camera.

Seven-year-olds Kristen and Erin know the best way to cool off on those hot California afternoons.



#### Mom's Turn:

I like to bring Kristen along when I need to do some shopping. It's wonderful to have an extra pair of hands to push Erin's wheelchair. Kristen enjoys these trips, too; when she comes over, she'll often ask, "Do you need to go somewhere today?"

With my permission, Kristen and Erin especially like to roam the store without me. As I shop, they stroll the aisles looking at things that are more interesting to kids. They also like to hide from me. Out of the corner of my eye, I often notice Kristen hurriedly pushing Erin by the end of the aisle I'm in, hoping I don't notice them. But I usually know where they are because Erin often makes a humming sound or grinds her teeth. Etched in my mind forever is a picture of Kristen pushing Erin's wheelchair down an aisle with one hand, while the other hand was wrapped around Erin's face to cover her mouth; Erin's hum was particularly loud that day and was giving away their position.

—Donna Tatro

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: Children's Page, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.











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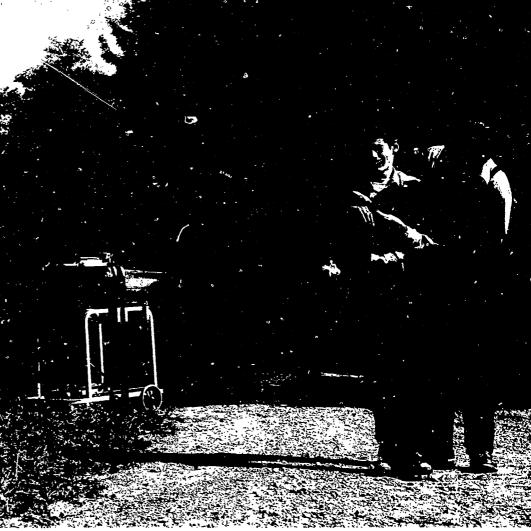






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# EXCEPTIONAL DARENT

The Magazine for Families and Professionals

AUGUST 1995 VOL. 25, ISSUE 8

PARENTING YOUR

CHILD OR YOUNG

ADULT

WITH A

DISABILITY

Since1971

Cover: Kelly Bankston, of The Orange Grove Center in Chattanooga, Tennessre, practices with Dr. Rick Rader for a presentation to medical students, interns and residents. Physicians in-training typically have little exposure to people with disabilities. Dr. Rader's innorative Developmental Disabilities Patient Simulator program (see page 36) aims to change all that.

Kelly, one of three "patient simulators" with developmental disabilities, "presents" a unique upper arm contracture and has learned to assist physicians in their approach and communication techniques. In Kelly's first outing, she suggested to a nervous intern that the doctor would get a better "feel" for the contracture by first removing her bulky ski jacket.

Kelly, 14. has verebral palsy, hydrocephalus, seizure disorder, visual and heaving impairments, curvature of the spine and a keen sense of humor. Photo: Dennis Wilkes.

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PAGE 29

# HEALTH

Genetic Counseling: Part One by Naomi Angoff Chedd	26
A New Twist to Playing Doctor by Rick Rader	36
TEACHING DOCTORS TO COMMUNICATE by David Lee Williams	36
Doctors by Kawanna Williams	38
The Friendly Skies by Michelle San Filippo Transportation need not be a barrier to medical care.	
Selective Dorsal Rhizotomy	41
Go For It! by Ryan Aas	41
EVALUATING "SUCCESS" by Jill & Hank Chambers	42
This Doctor's Point of View by Arthur H. Weber	
Understanding Enuresis	50
Food for Thought by Marsha Magol	52
Departments	
Editor's Desk	2
Letters	
Search & Respond	
Familiar Faces.	
Fathers' Voices: My Heart Swells with Love by John O'Hare	
Role Models: Heather Whitestone	
Point of View: The Value of Prenatal Testing by Alysoun Reichard	
Ask the Doctor: RHIZOTOMY?	
Media: Taking Charge; Uncommon fathers	
Health Insurance Troubleshooter: Conversion Rights	
What's Happening	
Directory of Advertisers	
Informational Forum: Networking	
New Products	
Exceptional Parent Library	
Children's Page: I'M PROUD OF MY SISTER by Caitlin Crossman	

# EDITOR'S DESK

# **IDEA** and **ADA**: Positive legislative changes

At the end of June, the U.S. Department of Education submitted its proposals to Congress to improve the Individuals with Disabilities Education Act (IDEA). These

proposals (see page 57) were based on input from more than 3,000 parents and educators. This will be the first substantial revision of the law since 1975.

In the last 20 years, this legislation has had a dramatic effect on



STANLEY D. KLEIN, Ph.D.

the lives of millions of children and adults with disabilities and their families, as well as on all Americans. Today, our society is far more welcoming and inclusive. We urge our readers to urge their legislators to support the reauthorization of this important legislation.

This summer marks the fifth anniversary of another important piece of legislation—the Americans with Disabilities Act (ADA). In its short history, the ADA has also contributed to far greater com-

munity participation for people with disabilities of all ages.

Both IDEA and ADA were enacted because parents and people with disabilities worked tirelessly to inform members of Congress about their needs. Today, with all the talk in Washington about returning to old ways of doing things, we need to remind our elected officials that the results of these legislative changes have been positive for *all* citizens.

#### Health

All too often, parents' relationships with health care professionals are not the partnerships described by Irene Pollin in her wonderful book, *Taking Charge* (see page 53). Sometimes, parents and professionals become adversaries and "forget" their shared concerns about a child's well-being.

Gradual changes in the education of professionals have contributed to increasing collaboration between parents and professionals—especially when parents and individuals with disabilities have become directly involved in the professional education process. In this issue, we are delighted to report on an exciting new program in which children and young adults with disabilities are teaching physicians (see page 35). We hope this program, created by Dr. Rick Rader, will serve as an example. We are also pleased that Dr. Rader has joined our Editorial Advisory Board.

Recently, professionals have started talking more about the emotions of parents of children with disabilities. Still rarely, however, do professionals discuss their own feelings. We know that such discussions—difficult as they may be—will be stimulated by "This Doctor's Point of View," an unfinished essay by the late Dr. Arinur Weber.

# **Special Olympics**

Thanks to our wonderful staff and friends, 75,000 copies of a special issue of EXCEPTIONAL PARENT were distributed at the 1995 Special Olympics World Summer Games. We enjoyed seeing the thousands of excited and proud athletes from all corners of the globe. A world in which the horrors of ethnic, cultural and class warfare occur all too frequently could learn much from these spirited, caring athletes who just happen to have intellectual limitations.

#### **Subscription prices**

Every few years, though cognizant of the financial burdens many readers face, I have the unwelcome task of announcing a subscription price increase. The costs of postage and paper have increased significantly. As a result, we must raise the price of a one-year subscription to \$28, effective November 1, 1995. The good news is that all subscribers will have an opportunity to renew their subscriptions at the current price. While we know our magazine provides valuable information, we also know that costs of so many things seem unfair. We appreciate our readers' understanding and loyalty.



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**₩BPA** 

ss Report

May 94

Before Dec. 92

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**Comments:** Bobby shows greater endurance and activity in the GS Cushion and Back.

Follow-up: Adjustments will be easy to make as Bobby continues to grow and develop.

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# LETTERS

# An Invaluable Resource

I am an occupational therapist, and your magazine is an invaluable resource for me. I have shared it with parents, used it to locate organizations and products, and have learned much from the articles I've read in it. It is very interesting and enjoyable reading—I prefer it to my popular and professional publications.

S.S., Illinois

#### **Cover to Cover**

Like so many of your readers, I sit down and read the magazine from cover to cover, just as soon as I can—usually within hours of its arrival in our mailbox! I am often touched by the articles and letters from parents, especially *Search* letters from parents of children with rare conditions. I feel grateful to have a daughter with a relatively common disability—Down syndrome.

I've passed articles on to other people. I've laughed, I've cried and I've even been outraged on occasion. Thank you for a wonderful, informative and up-to-date magazine that really hits the spot with me.

J.T., California

#### **Facilitated Communication**

My daughter and I were sitting in Dr. David Hirsch's office two weeks ago when I picked up the May issue of EXCEPTIONAL PARENT. After looking at the cover, I told my daughter that there was another article on facilitated communication (FC). I said a prayer that maybe *this* magazine had published a fair, up-to-date article, based on the facts.

Not to our surprise, but much to our disappointment, you did nothing but continue to print misinformation. Those of us with children who benefit from FC have never claimed that FC will benefit every nonverbal person. We ask only for fairness.

Why didn't you print an article by Dr. Doug Biklen—one just as long and detailed as the Levine/Wharton article—side-by-side with the nega-

tive article? Why didn't you list the Syracuse University FC Institute as an information resource? Why doesn't EXCEPTIONAL PARENT allow parents to make their own judgments about what may or may not work for their children?

My daughter is blind and nonverbal. Her use of FC has been validated by a competent psychologist. FC has changed her life; she now uses FC with seven different individuals. What else does my daughter have to do to prove her competence?

J.U., Arizona

■ I was appalled that the May issue of EXCEPTIONAL PARENT declared FC "not a valid approach to communication." Your coverage of FC was very unbalanced and clearly communicated a decision to "trash" FC. I understood that Dr. Biklen would present another point of view in another issue, but his article should have appeared in May. Your lead article on FC, the first ever by EXCEPTIONAL.

continued on page 6

EXCEPTIONAL PARENT

To reach out to parents of children and young adults with disabilities and special

health care needs and to the professionals who serve families

To empower parents and professionals by providing practical information and emotional support.

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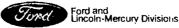
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continued from page 4

PARENT, seriously misrepresented this valuable communication method. I believe you have done untold harm for the future of FC, because there are parents who take the information presented in EXCEPTIONAL PARENT as "gospel." This article has the force to stop many parents and educators from pursuing the truth.

I've worked in the parent business for 21 years. I've talked to parents from all over the country. I've met and observed their children. I've listened to their tribulations and triumphs. I have been privileged to hear the reports of many FC successes, many FC disappointments and some FC failures. I'm sorry you haven't seen and heard the same things. I believe you've made a substantial error.

You neglected to speak to a number of experts before running this article. In fact, Rosemary Crossley was in the States at that time. Did you interview her? Did you talk to 1981 Nobel Prize laureate (physics) Dr. Arthur Schawlow, who has testified to the effectiveness of FC? Did you watch the video clips of Sharisa Kochmeister, who learned to communicate through FC and now types without any physical support?

By now, you know I'm upset and disappointed with Exceptional ENT. The most disturbing aspect of this controversy is that you have joined with certain "professionals," in opposition to parents. And just so you don't misunderstand, I have

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enormous empathy for parents like those who told the story about being falsely accused of abuse through FC ("An FC Nightmare"). Yes, there have been mistakes and abuses—plenty of them; most have been perpetrated by professionals. I work to stop these kinds of abuses.

For many years, Exceptional Parent has worked to empower parents. But in this case, you decided-not the parents. I believe you will learn that you were wrong. Next time, please call the real experts!

Patricia McGill Smith, Executive Director National Parent Network on Disabilities (NPND) Washington, DC

■ I was horrified when I read the article about FC in your May issue. Four years ago, I started babysitting for a beautiful three-year-old girl who had been born with a chromosomal disorder. She used sign language and knew about 100 signs.

Two years ago, a therapist introduced her to FC. Testing showed she had the vocabulary of a eight-yearold, but couldn't verbalize the words she knew. I was not surprised. I had always treated her like any other child the same age, but FC made my job a lot easier.

Not just anyone can facilitate. A facilitator must have faith in the child. He or she must also know how to hold a child's hand properly; pulling back on the child's hand not only prevents facilitator influence, it also gives the child stability and confidence.

The frightened three-year-old I met four years ago is now a first grader in a public school. She is in a regular classroom and can speak clearly using three- and four-word phrases. She points to what she wants without any physical guidance. She is confident in her own abilities; often, when I try to help her, she says, "By myself. Go away."

As for allegations of child abuse, it is imperative that we assume that children do not lie. My heart goes out to anyone who is wrongly accused of child abuse, but I would rather see someone falsely accused of abuse than see a guilty person not be accused. The story by the facilitator who "wrongly" accused a family of abuse disturbed me ("From Someone Who's Been There and Back"). The law requires school officials to report suspicion of child abuse within hours, not weeks. I wonder why it took weeks of facilitating by a number of people to report the suspected abuse, but only one day to label FC as evil.

B.T., Connecticut

# "Warm Fuzzy"

I'm a new subscriber, but wish I'd known about you a long time ago. I've already gotten so much good out of your magazine. Keep up the excellent work—this magazine is a real "warm fuzzy" in a very busy, hectic and bard world.

A.S., Illinois

continued on page 8



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continued from page 7

# Straight From The Heart

Like many people who write to you, I have a child with a disability. I used to feel like I was the only one with a child who has so many needs. I constantly prayed for all the problems to go away and for my life to be normal. I cried so much and was sad all the time.

My two-year-old son has cerebral palsy. He tries to talk and pull himself up, but he knows he can't. But he is always happy, laughing and playing. Whenever I'm upset or sad, he makes me smile. He always shows me how much he loves me.

I am 16 years old. I had to grow up real fast after my son was born, but if I had the chance to replace him with a "normal" child, I wouldn't c'o it for the world. I now realize how lucky I am to have him.

Children with special needs can teach you a lot about life.

I want to say how wonderful EXCEPTIONAL PARENT is; I've never

read any other magazine that makes me feel so good. All the stories are written by real people talking about their real experiences and feelings. It's straight from the heart.

C.B., California

# Hearing Impairment and Hearing Aids

I am writing in response to "Hearing Impairment and Hearing Aids" (May 1995). I am the mother of two children with bilateral hearing impairments, and although I agree with most points in the article, I disagree with the author's recommendation that a child's hearing aids be checked every three months. This could get quite expensive because most insurance companies do not cover any expenses related to the aids. These are out-of-pocket expenses.

With training from the audiologist on the use of the dri-aid kit, stethoscope and battery tester, most parents should be able to avoid problems or catch them if they occur. I have my children's aids checked yearly, or any other time a problem arises.

I'd also like to add a suggestion for other parents: it is a good idea to include on your child's IEP that he or she be seated at the front of the class. This will allow the child to maximize the benefits of his or her hearing aids with less auditory interference.

S.P., Iowa

## Fragile X Syndrome

Thank you very much for the *two* articles featuring fragile X syndrome that appeared in the June 1995 issue. I have been reading EXCEPTIONAL PARENT since my son was diagnosed with fragile X in 1991 and have seen this condition mentioned only rarely. I am a strong advocate for letting others know about this very common cause of developmental disabilities.

K.M., Virginia



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# SEARCH

# Supervising a "Runner"

My three-year-old son has autism. He is considered a "runner." If not constantly supervised, he will run away. If a door is left ajar, he can open it. Once outside, he'll run and run! It's very frightening. We have notified the local police department because Jimmy cannot talk, and if he ever got away from us, we wouldn't know how to track him down. We tried a "tracking device" attached to his clothing, but he would not keep it on.

I constantly fear for his safety. In south Florida, where we live, there is water everywhere! We keep the house locked up like Fort Knox and try to watch him at all times, but we're still afraid he might get away from us. Are there any other parents out there with a child who is a "runner?" Please help!

L.K., Florida

#### Two Undiagnosed Children

We are the proud parents of three lovely daughters, two of whom have disabilities. Our oldest daughter is from a previous relationship and is perfectly healthy. Our second child, Brittany, 3, was born with congenital heart defects (atrial and ventricular septal defects) and a neural tube defect which resulted in the tethering of her spinal cord (spina bifida occulta). Accompanying these defects are global developmental delays and farsightedness.

After Brittany underwent heart surgery, she developed reflux and tactile defensiveness, resulting in a refusal to eat, which caused failure to thrive. Brittany was evaluated by several geneticists. Although they mentioned that she had dysmorphic facial features, they assured us arittany did not have a syndrome; the results of chromosome studies were normal. These specialists did not believe we had any risk of having another child with the same disabilities.

After careful consideration, we decided to have another

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

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For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in EXCEPTIONAL PARENT'S 1995 Resource Guide (January 1995).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 967, Blue Ridge, GA 36513; (800) 651-1151 (V/TIY) or (706) 632-8830 (V/TIY).

child. The pregnancy was closely monitored. No problems were detected until the seventh month, when doctors found a problem with the placenta and recommended early delivery due to fetal distress. When our child was born, doctors discovered she had the same congenital heart problems and neural tube defects as her older sister. She also has dysmorphic features and global developmental delays. Again, chromosome studies appeared normal.

To this day, we have no diagnosis for our two youngest daughters; doctors are completely mystified. We would like to hear from anyone who knows of children with the same problems or characteristics.

M.M. & J.M., Ontario, Canada

## Unprepared

My son, Ian, was born 13 weeks premature and weighed only one and a half pounds. He had a grade I brain bleed and periventricular leukomalacia, a condition in which tissue around the brain's ventricles (chambers in which cerebrospinal fluid is made and circulated) is damaged due to insufficient blood flow or lack of oxygen.

We brought Iar home knowing things wouldn't be perfect, but we didn't realize how difficult it would be. He has recently been diagnosed with spastic quadriplegic cerebral palsy. At 21 months of age, he cannot sit, roll from back to front or crawl. He babbles but does not say any words. He has had two fundoplications with g-tube placement, and three bilateral inguinal hernias. He is scheduled for another operation to correct strabismus. He does not eat and the doctors still have not determined if this is due to a swallowing dysfunction. Doctors cannot yet make any determinations about Ian's mental and physical status.

Our family needs a nurse to come along with us when we do anything together. It is hard for us to imagine a whole life of planning every minute. What do other parents do if they want to take their child to a restaurant, to the park, to the mall? Because my husband and I both work, our income prevents Ian from getting any financial assistance. I wanted to get a tray accessory for Ian's new chair, but it costs \$400 and although the insurance paid for the chair, they will not pay for any accessories. How do parents obtain these items without going broke?

I would like to hear from parents with children who have any of the same conditions as my son. Any suggestions and all tetters will be greatly appreciated.

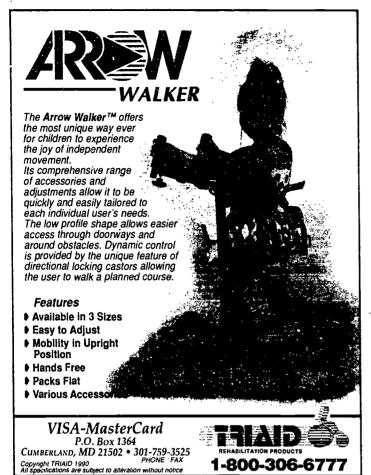
J.B., New Jersey

# Turner Syndrome, Opitz Syndrome, G-Tube Problems

Our youngest daughter, three-year-old Haley, has Turner syndrome (a chromosomal disorder affecting only females, caused by the lack of one of the X chromosomes in all or some of the body's cells) and Opitz syndrome (a rare hereditary disorder characterized by wide-set eyes, cleft lip and/or palate and swallowing problems). Haley has a double chromosomal cell line of 45XO, which is Turner syndrome, and

continued on page 12





Circle #48



# SEARCH

continued from page 11

47XXX. Because of the Turner syndrome, Haley is very small (32 inches tall and 23 pounds) and has no ovaries.

Haley has never eaten food; she drinks a predigested formula. At 10 months, she had a fundoplication (a surgical procedure to correct severe gastroesophageal reflux) and a gastrostomy (insertion of a g-tube for feeding). She chokes on her formula and saliva.

Haley has bleeding stomach ulcers and a paraesophageal hernia from extremely forceful internal pressure. Because of this pressure, 29 g-tubes have blown out of her stomach with 10 cc of fluid still in the balloon. Haley recently had a pyloruplasty (repair of the valve between her stomach and small intestine), but this procedure did not help her pressure. Bile now comes up through her tube, along with her stomach contents. We must vent the tube constantly.

Despite Haley's many problems, she is bright, alert, happy and mobile—thanks to braces and years of physical therapy to deal with hypotonia (low muscle tone). She has talked since she was eight months old and now converses in complete sentences.

We would like to communicate with other parents who have a daughter with Turner syndrome along with other diagnoses or difficulties, or with anyone who needs to vent their child's g-tube constantly, with contents continuously rushing back.

 $\it J.E., Pennsylvania$ 

Entron's Note: These organizations may be able to provide useful information and support regarding some of Haley's disabilities: Turner's Syndrome Society of the U.S. (15500 Wayzata Blvd., #768-214, 811 12 Oak Ctr, Wayzata, MN 55391; 612/475-9944) and Opitz Family Network (P.O. Box 516, Grand Lake, CO 80447; 303/627-8935).

#### Chromosomes 2 and 14

One of my two-year-old twin daughters has been recently diagnosed with a balanced translocation of chromosomes 2 and 14. Unfortunately, nobody seems to know much about these two chromosomes, so no one can answer our questions about her future. She has developmental delays, especially with her speech.

I would like to hear from another parent whose child has this type of chromosome abnormality.

P.B., Virginia

### **Bowing of Tibia and Fibula**

Our two-year-old son, Jacob, was born with posterior medial bowing of the tibia and fibula (the two bones of the lower leg). We are desperately searching for information and other families dealing with this condition.

B.A., Florida

#### Partial Trisomy 15

1 %

Our son, "TJ," has been diagnosed with partial trisomy 15. Our doctor says this condition is fairly rare. We would appreciate any information from any source.

T.N., Florida

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# RESPOND

## **Swinging Objects**

C.T. (April 1995) has a 16-year-old son with Down syndrome. He also takes Synthroid for hypothyroidism. Since he was a baby, he has had a tendency to focus on objects that he can hold and swing around. Often, as he swings the object, he talks to himself, and sometimes, he spins in circles. At these times, he seems to "zone out." As he has gotten older, these behaviors have increased. C.T. is looking for any suggestions for trying to understand and lessen the frequency of this behavior, if not eliminate it altogether.

My four-year-old daughter has Down syndrome. She also loves to focus on objects and swing things in front of her eyes, while babbling and talking to herself. It is quite easy to interrupt her to get her back to task, but I, too, am concerned about how she can "zone out" everything.

She has been doing this single she was a baby, and the pediatricians and development specialists say not to worry. They tell us to keep distracting her or take away whatever she is swinging and show her what the object is used for. But I am still very worried.

A specialist told me that because my daughter is affectionate and can make eye contact, her behavior indicates self-stimulation, not autism. She has also undergone careful evaluation of her hearing and vision.

If you get any suggestions that seem to work for your son, I would appreciate hearing about them.

G.R., Newfoundland, Canada

■ We are the parents of a seven-year-old boy, Brett, who has Down syndrome. Our sons would probably get along great! Brett also enjoys swinging one of his toys and spinning in circles. While doing this, he often babbles or hums. At these times, like your son, Brett seems to "zone out" everything around him.

We try to offer Brett different things to do so we can distract him from spinning this toy. He has gotten to the point where he becomes very angry and screams when we take the toy away from him. I would be very grateful for suggestions or ideas.

Y.S., New York

# **Omphalocele**

L.S.,(April 1995) has a six-month-old daughter who was born with a large omphalocele; her entire liver was outside of her body. She was looking for information about the development of children born with this condition including growth patterns, motor skills, weight gains/losses and feeding difficulties.

My three-year-old son, Adam, was born 10 weeks premature with an omphalocele. His entire liver was concealed in a thin sac on the outside of his stomach. When he was two days old and only three pounds, doctors performed surgery to "push" his liver back in. He has a fairly large scar on his str mach and no belly button, but he is healthy as can be. F.e has *no problems* related to the omphalocele. We have had a few stitches work their way out over the years, but that hasn't been a problem.

As a totally unrelated condition, my son has cerebral palsy. He is very verbal, and totally non-ambulatory. Someday, I will have to explain to him why he doesn't have a bel'y button. For some reason that seems so inconsequential compared to trying to explain why he can't walk. We don't know what caused the omphalocele, and probably never will. I am pregnant with my second son now and pray every day for a healthy full-term baby.

L.V., Wisconsin

## Dealing with Seizures

D.R. (May 1995) has a son, Christopher, who is almost three years old. He has cerebral dygenesis, meaning that roughly half his brain is gone. He has developmental delays, hypotonia, slightly clubbed feet, farsightedness and a seizure disorder that is mostly controlled by Dilantin. But when Christopher does have a seizure, he stops breathing. D.R. wanted to know how other parents deal with seizures, especially how they sleep at night.

Our son is five and, like Christopher, also has a seizure disorder. He has developmental delays, hypotonia and visual impairment, but is otherwise very healthy and happy. Currently, his seizures are fairly well controlled by medication.

Like Christopher, our son has difficulty breathing during and after a seizure. He doesn't actually stop breathing, but his breaths are very shallow and irregular. His seizures always happen while he is sleeping. We had to call the paramedics during the last one because he had such a hard time recovering from it—he was struggling for air and his heart rate remained high. After they administered oxygen, he relaxed and went back to sleep. We have since obtained in-home oxygen to use in these situations; this has given us amazing peace of mind.

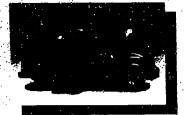
To answer your question about how we sleep at night, we still use a nursery monitor. I am a light sleeper—differences in my son's breathing, or the smacking sounds he makes when he is having a seizure, wake me up. Mother's intuition may also play a role; sometimes I've been in a deep sleep and I've begun to dream that he is somehow in trouble or that someone is trying to hurt him—only to wake up and find him having a seizure.

Our son has a fear of going to sleep by himself. This fear developed about the same time his seizures started. So anytime he has a fever, I will just sleep in his room. Although some people may frown on the practice, I see nothing wrong with sleeping in the same room as your son if that makes everyone more comfortable. We fought that solution for several years, but after many tears and sleepless nights, we finally decided it would be better for everyone.

C.A., Arkansas



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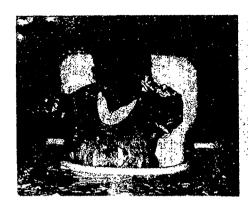


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The Braun Corp ration is the international leader in mobility products. With four divisions and a worldwide All-Star Distributor network, we are positional to provide the equipment and service you need. Our commitment to your satisfaction is also supported by our Three-Year Worry-Free United Warranty, Simply call 1-800-THE LIFT for the Braun All-Star nearest you.

# ramiliar faces



At least he wore a bib! As 26-month-old Matt Boysen demonstrates, a simple household item, like Dad's shaving cream, can provide hours of fun. In fact, Matt needed only a few minutes to cover himself—and everything else he

could get his hands on—in the foamy stuff. Matt, who has Down syndrome, lives with parents Dirk and Carey in College Station, Texas.



Tina Dockray, 10, of West Milford, New Jersey, enjoys her family's annual vacations to Wells Harbor, Maine. She especially enjoys the water, even though she has to be careful not to get her tracheostomy wet. When not on vacation, Tina, a third-grader, enjoys reading, writing and playing t-ball. Tina, who has congenital myotonic dystrophy, is the first child with disabilities to play on a regular t-ball team in her hometown.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!



The camera caught sevenyear-old Jennifer Ann Carter with curlers in her hair! Well, at least she'd gotten her nails painted before Mom started snapping away. Jennifer, who lives in Clearwater, Florida has nonketotic hyperglycinemia, a rare metabolic disorder. Doctors said she would not live to six months of age; she's 10 now.

It takes more than a sudden downpour to dampen the spirits of a vacationing Justin Oneal! Justin, who has cerebral palsy and halls from Mt. Vernon, Georgia, loves to travel; his favorite word is "go!" When the weather turned soggy during a visit to Zoc Atlanta, 20-monthold Justin was having too



much fun to leave. So, mom Regina rushed to purchase and put together some makeshift rain gear—a stroller-mounted umbrella, a rain hat and a couple of plastic bags.



Yeeee-hah! Cowgiri Kylie Linton Moullen, 4, of Bellingham, Washington, gets a giggle out of trying to fill her daddy's boots. Kylie's mom, Marilyn, says doctors consider Kylie a "mystery." She has a seizure disorder, some rare metabolic deficiencies, a sensory integration disorder and dysautonomia. "But," says Marllyn, "she's every bit as goofy as the next kid."



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# rathers voices

# My Heart Swells with Love

by John O'Hare

s I watch you sleep, all curled up clutching your little panda bear, my heart swells with love and pride. I look back on how far you've come in your short life, and I think about all the obstacles and challenges you have faced and conquered. I don't think you will really ever know what a little hero you are to your mom and dad.



When Dad arrives home from work, Ryan, 9, gets in some "lap time."

When I first saw you, just nine short years ago, I was torn between so many different emotions. I was thankful, but I had so much fear and apprehension because the doctors had told your mom and I to prepare for the worst. You had beaten so many odds just by being here, but we still didn't know what the future would hold. We were not even able to hold you before you were whisked away.

The first time your mom was allowed to hold you, she could not

In the neonatal intensive care unit, John held Ryan for the first time. Ryan, one day old, had already undergone his first surgery.

hold back the tears. You were so little and fragile, but so beautiful. Those first few days had been so hard—watching you lying there in your little bed and being unable to hold you. We could only visit a few times each day, but we lived for those times. You were so tough, and as you grew stronger, your will to fight amazed all the doctors

and nurses.

I look at you now, sleeping so peacefully. We had such fun today. Your mom sometimes asks if it bothers me that you can't do so many things other little boys your age can do-things like playing ball or running with other children. I always tell her no; it is such a joy just to have you, and to be able to do all the things we do together. You enjoy life so much and are so happy doing the things you can do; I see no reason to be sad. I only have to recall your silly, crooked little smile as we rode the roller coaster at the amusement park last weekend, or think about how excited you get whenever you see a train go by. You may not be able to do some things, but you live life to the fullest, little boy.

I could stand here watching you for a long time, but I'm afraid I may awaken you. I once read that special children are a blessing from God. l

Fathers' Voices is a regular feature of Exceptional Parent magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their chilm's and families' lives.

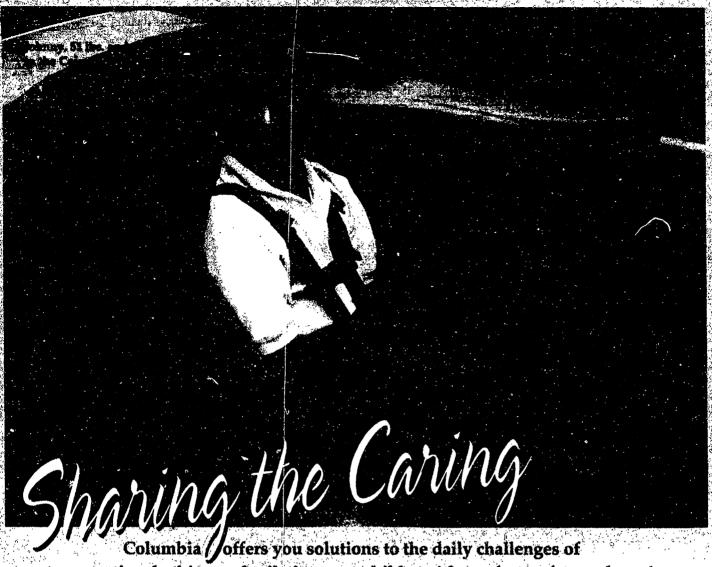
believe that now. Always remember, you are loved so much. Sleep peacefully, little Ryan; we'll see you in the morning. **EP** 

John O'Hare, 43, lives in Charlotte, North Carolina with his wife, Diane, and son, Ryan, 9. John is a 20-year veteran of the Charlotte-Mecklenburg Police Department, where he currently holds the rank of Captain.

Diane, a registered nurse, works weekends, so Saturdays and Sundays are "buddy days" for father and son—as John puts it, "a wonderful opportunity for me to develop a very special relationship with a very special child."



There's nothing like a bedtime story—especially when it's read by Dad!



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### kole wodels

## **Heather Whitestone**

"Yes, you can!"

On September 17, 1994, 21-year-old Heather Whitestone became the first woman with a disability to be crowned Miss America. Whitestone, an accomplished ballerina, has been profoundly deaf since the age of 18 months. After the new Miss America is crowned in September 1995, Whitestone, who currently logs more than 20,000 miles a month in public appearances, will return to Jacksonville State University in Alabama to continue her studies in accounting.

Last April, during a visit to Boston, Whitestone took the time to speak with Exceptional Parent associate editor Kim Schive. The following was adapted from that interview.

hen I was 18 months old, I had a high fever and almost died. The doctors gave me a medication that caused my deafness. My parents figured out I was deaf soon after I came home from the hospital. My mother dropped some pans in the kitchen; it scared everybody in the family except me. I just kept playing with my toys.

At first, my mother felt angry. She didn't want me to be deaf. She wished she could take my deafness for herself. But then she started to look at the situation as an opportunity for creative ideas. She began to investigate methods of communication and education, like the oral approach [speaking and reading lips], total communication [using sign language along with speech] and the acoupedic approach, which means training a child to listen with a hearing aid.

My mother visited classrooms where different methods were used. She was most impressed with acoupedic training, because the children in those classes came right up to

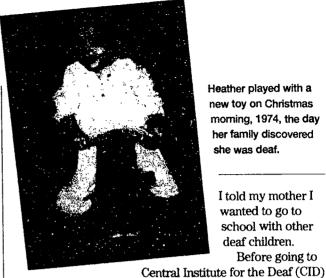
her and talked to her. She felt free to communicate with them. When she met students who used sign language, she felt awkward. She had to use an interpreter to communicate with them. She wanted me to be able to communicate with everyone, so she chose acoupedic training.



Heather, 5, attended a regular kindergarten with hearing children.

#### "I knew I was different."

I went to a regular kindergarten with hearing children. I knew I was different. I was the only deaf student. I stayed in public school through fourth grade. Then



Heather played with a new toy on Christmas morning, 1974, the day her family discovered she was deaf.

I told my mother I wanted to go to school with other deaf children.

Before going to

in St. Louis. I had never met other deaf kids-maybe just one little girl, who was younger than me, at the speech therapist's office.

When I arrived at CID, I had mixed feelings about seeing all the other deaf children. In one way, it felt very strange.

I lived in the dorm. At first I loved it. It was like having a slumber party all the time. But it was stressful, too, because there were so many children around all the time.

The other students were interesting; they came from all over the United States and the world. I had friends from Mexico, South America and Kuwait. It broadened my horizons.

My best friend was from Canada. She was a very determined girl. I admired her because she never let anybody stop her. But some of the other deaf students had very low self-esteem; they used their deafness as an excuse all the time. They would say, "You're deaf, you cannot do it." I didn't like to be around those kids.

CID was a great school. My first year there, I advanced two grade levels. The school had very small classes-like three or four students in each-and the teachers knew the best way to communicate with me.

#### The real world

When I was 14, I returned to public school. It was ninth grade, the beginning of high school. I remembered some of the other students from when I was in public school before. But they had changed so much. Ther was a lot of peer pressure; kids fooled around with drugs, a inking and sex. I didn't want to do any of those things. I cause I those to be true to myself, I did not fit in with the crowd.

The second problem was that the other kids were a little bit afraid to communicate with me. Even though they saw me speaking, they thought I would not understand them. They would say, "Oh, Heather is deaf. I have to sign to her! She would never understand me!"

So some of the kids learned some sign language. Two of them would keep coming up to me and signing to me—without their voices. It was a little embarrassing. They were only seeing my deafness, not my heart and not my abilities.

I was like, "I'm sorry, but I don't know sign language!"

High school was lonely. In those four years, I had only three friends. I practically had to beg a guy to take me to the prom and homecoming

Heather remembers her years at a hearing high school as lonely. "But," she said, "It taught me what I needed to do to survive in the real world." dance-and now I'm Miss America!

But I don't regret that I went to a hearing high school. It taught me what I needed to do to survive in the real world. I learned to take responsibility for educating people who don't understand my problems. Let's face it—the world has more hearing people than deaf people. When I go to the airport, I don't see deaf people. When I order a hamburger at McDonald's, I don't order my hamburger from another deaf person.

"HIGH SCHOOL WAS LONELY.
I PRACTICALLY HAD TO BEG A
GUY TO TAKE ME TO THE PROM
AND HOMECOMING DANCE."

Yes, I get lonely. That's part of having a disability. Anyone with a disability probably experiences some loneliness every day. And I get tired of always having to educate people about how to communicate with me. Sometimes, I hate it... I hate it, but that's the real world.

continued on page 24

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#### Role Models

continued from page 23

#### **Becoming Miss America**

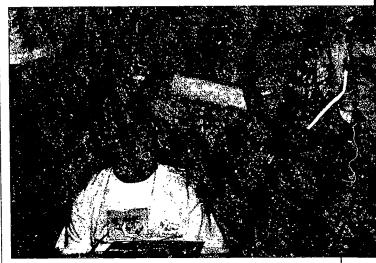
One of the first local pageants I entered was the Miss St. Clair [Alabama] pageant. I didn't win anything, probably because my first interview with the judges did not go well. They acted so awkward. I thought they did not like me because of my deafness. I was sure that was why I did not win.

Later, my family watched a videotape of the interview. They told me, "Heather, we don't believe you lost because of your deafness; it was how you handled it. You did not master the situation."

My family was right. I had not told the judges what to do in order to communicate with me.

Two weeks later, I was in the Miss Jacksonville State University (JSU) pageant. This time, I had a wonderful interview because I told the judges how to communicate with me. I asked them to look at me, and to talk slower so I could read their lips. The judges felt at ease with me after I explained this. And I won the pageant!

As Miss JSU, I had the chance to go to the Miss Alabama pageant. I won first runner-up. I went back to Miss Alabama a second year—and I was first runner-up again! But the third year, I won. Finally, I had my chance to compete for Miss America; but in Miss America, you only get one chance.



During the first seven months of 1995, Heather has logged more than 20,000 miles a month in her travels as Miss America. She spent the moming of June 10 meeting children at the SHHH (Self-Help for Hard of Hearing People) convention in Dallas, Texas, where she helped young Lauren Thompson adjust the Miss America crown for a picture perfect pose. (Photo courtesy of Oticon 4 Kids.)

Some people say I won Miss America because I am deaf, but that's not true. I believe I won Miss America because of my determination and my education. In fact, I was not even the first deaf contestant. Six years ago, Miss

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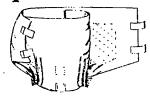
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Washington [Jennifer Wall, 1989] was the first deaf contestant at the Miss America pageant. She did very well; she finished in the top ten.

She always was there for me—whenever I succeeded, whenever I failed. And she always said, "You can do it, Heather. Yes, you can!" **EP** 

#### Making a difference

As Miss America, I hope that I can make an impact on some people. I want to help people with disabilities believe in themselves, and I also want to raise awareness among people without disabilities.

So far, I have received more than 5000 letters. One was from a deaf girl, the only deaf girl in her high school. She said that before I won Miss America, she was not sure people would be willing to be open to people with disabilities. But after I won Miss America, she began to have more confidence in herself. And this year, she was nominated to be her school's homecoming queen.

A friend of my mother told me a story about a little girl in her neighborhood. The little girl, a hearing girl, decided she wanted to dress up as Miss America for Halloween. And her mom helped her dress up with a white gown, white shoes, a crown and a scepter. She had everything, and she looked beautiful. But she cried because her costume was not right. She told her mother she couldn't go out trick-or-treating—because she didn't have a hearing aid!

#### Yes, you can!

Whenever I talk to kids, I tell them, "I believe in you. You can do whatever you want to do; you can do it!" One time I said that to the kids I met while visiting a school for children with disabilities. Some of the kids had severe cerebral palsy and couldn't move much; some had mental retardation.

Reporters were following me around while I talked to the kids.

Later, the press was very hard on me. They asked, "Why did you tell those kids they can do it? Look at them! They can't do anything."

At the time, this made me feel really bad. But later I was thinking about it and I thought, "If I were one of those kids, I would want to hear that someone believes in me."

My mother always believed in me.

#### Mom writes about Heather and ballet...

Fortunately for Heather, she had her dance, because the rest of her daily life—at least during the school year—consisted almost entirely of... long hours of speech therapy and schoolwork. Any recognizable progress in those areas came slowly and at a great price.

Dancing was different. For Heather it was pure joy. I think one reason she enjoyed her dance class was because students seldom had to speak or answer questions out loud, so she didn't feel so different. She fit into the crowd and felt just like everyone else out on the dance floor. She believed she could dance just as well as anyone else in her class—maybe better.

I knew there were still some people who had a hard time understanding how or why a deaf child would be taking ballet. I vividly recall a conversation I overheard early one Saturday morning during a dress rehearsal for a recital. Sitting by myself in a row of seats out in the auditorium, watching Heather's little troupe practice their numbers, I caught just enough of something said behind me that I began to listen carefully. I didn't turn around to look, but two mothers I didn't know, who evidently also had daughters up on stage, were talking about Heather. "She's deaf, you know. Can't hear a thing. I don't know what she's doing in dance class anyway; it's a shame Tracy let her in. I just know she's going to mess up tonight and ruin the whole program."

I had a thing or two I wanted to say to those ladies. But for once I simply bit my tongue and let it go... By this time, no one could have said anything to make me pull Heather out of her ballet. I saw how much it meant to her. And I felt it invaluable for her to have something that was all hers. Something she didn't do because it was expected or required. Something she did purely for love.

Dance performances also gave Heather a welcome chance to shine in public. My family—my parents, Stephanie and Michael—would drive all the way down from Birmingham for her recitals. They always made such a fuss over her afterwards that I'm sure Heather thought she'd been the star of the show. I felt that affirmation was good for her.

Another one of the joys Heather got out of her ballet I didn't fully understand until her teacher Jeannette Sutherland told me this story... In class one day she asked the children to tell one thing they did when they wanted to irritate their brothers or sisters... When Heather's turn came, she walked to the front of her class and got this incredibly mischievous grin on her face. Then she explained that if she wanted to make her sisters, Stacey and Melissa, really mad, she waited until they were watching their favorite Saturday morning cartoons, then she'd begin dancing back and forth across the room. She demonstrated with

a little twirl and laughingly told her classmates, "I go front TV; they get mad and yell."

As Jeannette related the story, I couldn't help but laugh. I'd seen Heather pall that sturit many times, though I'd never realized she'd done it deliberately to a gravate her sisters. I'd always thought she was just so engrossed in her dance routines that she was oblivious to what her sisters were doing, or to their words when they would yell at her—"Cet out of the way, Heather! Who do you think you are any way? Miss America or something?"

Taken from the book, Yes, You Can, Heanest by Dephne Gray, © 1995 by Dephne Gray, Used by permission of Zondervan Publishing House. This book is available at your



Heather began taking dance classes at the age of five. By nine, she was an accomplished ballerina. "I encourage parents of children with disabilities to give their children opportunities for activities with other children after school," she says. "it was very important to me."





# Health

# Genetic Counseling "The science is the easy part"

PART ONE

by Naomi Angoff Chedd

Charlie and Jennifer Ross were just over 30 when they got married five years ago. They were healthy, gainfully employed and eager to start a family. Jennifer was thrilled when she got pregnant "the first time out of the gate," as she put it. She spent the next eight months reading all the right books, decorating the nursery and cutting back to a part-time work schedule. Her labor and delivery went smoothly; both Charlie and Jennifer felt they were the luckiest people on earth.

When their daughter Alyssa was diagnosed with cystic fibrosis (CF) two months later, it was like a bolt from the blue—"an eight on the Richter scale," says Charlie. They had heard of the disease only vaguely, and neither knew of anything similar in their family backgrounds. They didn't know where to turn for help, until their pediatrician suggested they consult a genetic counselor. "A what?" asked Jennifer.

enetic counselors are the savvy and eloquent people you see being interviewed as part of news reports on major breakthroughs in our knowledge about the cause or treatment of a devastating illness or the discovery of a cancercausing gene. But for Charlie, Jennifer and Alyssa, genetics is more than a talk show topic. The Rosses, and thousands of other families, are the people behind the headlines; they know all too well that advances in genetics are making life harder and easier at the same time.

What is genetic counseling? The mother of a six-year-old with Down syndrome put it well when she said, "In two one-hour sessions, our counselor taught me everything I wished I had remembered from Biology 101, Psychology 101 and Philosophy 101." Genetic counseling draws on knowledge from these fields—and others—in an effort to provide the most accurate, up-to-date information on the causes and treatment of genetic disorders, the tests available for identifying them, a possible prognosis for a child with a genetic condition and the prospects for future pregnancies.

Who does genetic counseling?

After Alyssa was diagnosed, the Rosses consulted a certified, Master's-level genetic counselor, one of about 1200 in the United States. But a family with a child who has a genetic condition may also receive useful information from their family practitioner,

obstetrician, pediatrician, a neonatologist, a nurse with a subspecialty in genetics or a geneticist with in-depth knowledge of their child's particular condition.

Although different professionals provide genetic counseling in slightly different ways, they all agree it is a process of communication. "We help families look at the big picture, not just the medical diagnosis," says Kathryn Spitzer Kim, director of clinical placements for Brandeis University's genetic counseling program, one of only 20 such programs in the country. "We also talk about the social, educational and financial considerations."

A good genetic counselor should have first-

rate knowledge of genetics. But he or she should also be able to communicate that knowledge in easy-to-understand language. And, according to Barbara Bowles Biesecker, genetic counselor and section head at the National Center for Human Genome Research, National Institutes of Health, genetic counselors must be able to listen as well as talk. "People are terrified when they get a diagnosis," she explains. "They often ask, 'Why did this happen?' They already know the scientific explanation; what they are really asking are the more soulsearching questions—'How will I cope? Will I be able to love and accept this child?' Genetic counseling is much more complicated than explaining percentages. Actually, the science is the easy part."

Charlie and Jennifer agree. "We didn't want to spend the rest of our lives searching for genetic clues in our family backgrounds; we wanted to find help, people who understood what we were going through. We just wanted to talk."

#### More than prenatal testing

Possibly the most important thing families can get from a genetic counselor is time—time to process a lot of information, time to ask questions, time to consider options and, perhaps, time to grieve the considerable losses they may experience.

A genetic counselor can provide a tremendous amount of information about local and national resources. He or she may

About this series:

It is impossible to discuss genetic counseling without acknowledging its far-reaching medical, legal; moral, economic, political and religious implications. However, the two articles in this series will be limited to the practical aspects of genetic counseling—what it is, who does it and how it can enhance or perhaps further complicate the lives of parents, professionals and especially our children.

Part II will focus on some available pre- and post-natal tests and profile several families—the chances they took, the choices they made and the little and the several families.

also be able to explain the practical implications of recent research results. Jennifer says, "Every time we hear anything about CF, we get so excited. We hang on every word, hoping for a cure. Our counselor has explained that while science is a lot closer, they're not about to knock at our door with the cure tomorrow."

Although a clinical geneticist or other doctor can also explain the medical consequences of a particular disorder or disease, physicians tend to be less neutral regarding options in the event of a prenatal diagnosis; this is particularly true of physicians working in managed health care organizations. In some cases, they may make the recommendation to terminate a pregnancy. After all, it is not to the economic advantage of an HMO to have a lot of kids being born with special (translation: "expensive") health care needs. A genetic counselor will not—or at least, should not—be directive.

Another advantage of working with genetic counselors is that they are often familiar and comfortable with conditions other medical professionals rarely see. While your pediatrician might see two children a year with your child's disability, a genetic counselor may see two a week. "One of the best things our counselor did was hook us up with other parents. Nobody can understand what we're going through except other CF parents," says Jennifer.

If your child does not have a diagnosis, you are not alone. One-third to one-half of children with abnormalities have no diagnosis. Perhaps your child's condition does not yet have a name, or nobody is willing to call his or her particular group of symptoms by a name, because it may not be a precise fit. But a genetic counselor may still be able to help you tap into resources, organizations or support groups.

#### Should you see a genetic counselor?

Different families seek genetic counseling for different reasons. A couple with a newly-diagnosed infant or young child, for example, will probably want a comprehensive explanation of the child's condition and likely prognosis. They may also want to know the chances of this or another birth defect occurring in future pregnancies.

A family with an older child or more than one child may be

thinking about reproductive issues for all their children—for example, the odds that a sibling without the condition is carrying the defective gene.

Betsy Gettig, a 15-year veteran in the field and past president of the National Society of Genetic

Counselors, says that couples or individuals can expect genetic counselors to provide three important things:

- Reproductive information: What are the chances of certain diseases or genetic conditions occurring in a current or future pregnancy? Are there ways to reduce the risks? Are there successful pre- or post-natal treatments?
- *Prognosis:* What is the likely course of a given disease or condition? How will a given child be doing in one, five or 10 years? While no clinician can predict the future with absolute certainty, they usually can provide the range of possibilities.
- Advocacy and support: People sometimes make decisions that aren't accepted by family members, friends or even personal physicians—trying an experimental treatment, for example, or choosing to continue

or terminate a pregnancy. Genetic counselors try to ensure that their clients make carefully considered choices based on accurate information; then they support them in the decisions they make.

According to Philip R. Reilly, M.D., clinical geneticist, lawyer and president of the Shriver Center for Mental Retardation, the following people may benefit from consulting a genetic counselor:

- Families in which there is a known genetic disorder, such as cystic fibrosis, Huntington's disease or hemophilia.
- Couples who come from the same ethnic group, when that group is known to have a higher incidence of certain disorders. Tay-Sachs disease is common among Ashkenazi Jews, for example, and one in 12 African-Americans carries the gene for sickle cell anemia.
- Families in which there have been multiple miscarriages, stillbirths or a childhood death from unknown causes.
- Women older than 34 who are pregnant or planning a pregnancy.
  - Relatives—especially siblings—of a child with a genetically-transmitted disorder.

Genetic counseling provided Charlie and Jennifer Ross with the information and support they needed after their daughter's diagnosis. Almost three now, Alyssa is doing well, and although they understand the range of possibilities for Alyssa's future. Charlie and Jennifer think "she's going to be around for a long, long time." They add, "We're even thinking she might like a little sister or brother."

Naomi Angoff Chedd is a member of Exceptional Parent's editorial staff.

#### How do you find a genetic counselor?

Your pediatrician or the geneticist at your HMO or hospital may be able to refer you to a qualified genetic counselor. Your state's department of public health may also be a good resource. Or contact one of the following organizations:

#### National Society of Genetic Counselors

233 Canterbury Dr Wallingford, PA 19086-6617 Requests for information and referrals must be received in writing. NSGC does not maintain or disseminate information about specific genetic disorders.

#### Alliance of Genetic Support Groups

35 Wisconsin Cir #440 Chevy Chase, MD 20815-7015 (800) 336-4363 (301) 652-5553 (301) 654-0171 (fax) Provides referrals to genetic counselors, support groups and other resources nationwide.



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### Point of View

# The Value of Prenatal Testing

by Alysoun Reichard

ike many women who identify themselves as opposed to abortion, I used to think prenatal testing was only for women who believed in abortion. In the past few years, however, my perspective has changed dramatically.

When I finally became pregnant after six years of infertility, I worried that I would miscarry, but I never really worried that my child might have a problem. I had an alpha-feto-protein (AFP) test because I had taken a fertility drug and was curious to know if I was carrying twins. When the results came back elevated, I still wasn't concerned. I figured it was either twins or an error.

There was never any doubt in my mind that I wanted my baby. So when my daughter was diagnosed with spina bifida during the follow-up ultrasound, in the nineteenth week of my pregnancy, I made it very clear I had no intention of terminating.

Over the next few weeks, I was repeatedly asked to explain my strong desire to have this child. The infertility specialist told me I should be able to conceive again, if that was my concern. But that wasn't it. What it really came down to was this—we did not conceive our child to play football with her. We didn't keep her because we were afraid we would "burn in hell" if we aborted.



Alysoun Reichard and daughter Heidi, 20 months, enjoyed the fall foliage at Sleeping Giant Park in Hamden, Connecticut.

We kept her because we loved her, we wanted her, and there wasn't anything that we wanted to do with a child that she would not be able to do.

#### The counselor's role

I fully believe that genetic counselors should remain neutral on the issue of abortion. They should offer families a clear picture of the implications of their findings, and then allow them to make their own decisions. However, I do not believe that rattling off a list of intimidating medical conditions constitutes offering a clear picture.

I also believe that it is inappropriate for a genetic counselor to speculate even when asked—about what he or

she would do in a given situation. First of all, it is a question that is impossible to answer. By 24 weeks gestation, a pregnant woman has already developed a relationship with her baby. She is showing; everyone knows she is

pregnant. She has felt the baby move. The counselor may feel able to weigh the decision objectively. However, in the same situation, she might find herself considerably less objective.

Mostly, however, I feel that a woman needs to make this decision within the context of her own value system. In her darkest hour, whatever she decides, she needs to know it was her own decision. This is a mighty burden to bear. A counselor may be tempted to try to help her shoulder it, but that is not part of the counselor's role. The counselor's responsibility is to give the

woman as much information as possible to help her make this decision on her own. If a woman truly seems unable to decide, I believe it would be more appropriate to bring in an additional advisor—a social worker perhaps—rather than violate the neutrality of the genetic counselor.

As prenatal testing becomes increasingly routine, genetic counselors will find themselves serving more and more women who are either ambivalent about, or opposed to abortion. These women deserve an approach that is respectful of their values. Their babies deserve the benefits of early diagnosis, but they will not have that benefit as long as women are distrustful of genetic counseling. One of the most common questions I am asked about my experience is, "Did they try to get you to have an abortion?"

Fortunately, I am able to answer emphatically, "No, they did not. They were very supportive of my decision." But the very frequency of the question underscores the distrust that exists.

#### An "informed decision"

Though I was never pressured to terminate my pregnancy, I was asked repeatedly whether or not anyone had discussed my options with me. Until I

continued on page 30

Heidi—aka "Winnie-the-Pooh"—celebrated Halloween 1992 with preschool buddies (from left) Brian Smith and Taylor Valentine.



oped a relat ship with he baby. She is showing; ev one knows: continued from page 29

reached the third trimester of my pregnancy, every new practitioner I metand there were quite a few-seemed to feel it was his or her personal responsibility to establish that I was making an "informed decision."

i would like to suggest a simple solution to this potentially upsetting problem. I believe there should be one member of the team—whether it be the genetic counselor or the social worker-who is designated to verify that the patient has reached an informed decision. Once a decision has been made, a bright red sticker should be placed in a prominent position on the patient's file, indicating to all other practitioners that they do not need to bring up the subject. If doctors fail to see a sticker on a woman's folder. they can simply inquire as to whether she has had the opportunity to talk with the counselor, or social worker, or whomever the designated person may be.

When a woman is undecided, she is sometimes offered the opportunity to



meet with the family of an affected child. I have already stated that I am opposed to abortion, so you may be surprised to hear that I feel such a meeting to be totally inappropriate. If a family has decided to keep their baby, I would be more than happy to meet with them, but I could not possibly meet with them before that time.

First of all, there is absolutely no way I could be neutral. My daughter is my pride and joy. Beyond that, no two children with spina bifida, or any other disability, are alike. My daughter's condition may be very different from that of

A fashion tip from five-year-old Heidi-If you simply can't choose between two equally lovely hats, wear both!

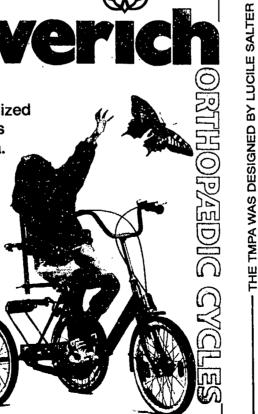
their child. Also, I would feel as if I was giving this family the opportunity to judge the value of my daughter's life in order to decide whether they should give their own child life. As my daughter got older, I

would worry that she might pick up on that aspect of these meetings.

Still, the opportunity to see living, breathing children-rather than hearing a list of medical conditions, could be very helpful to families in the decisionmaking process. The ideal solution may be for a neutral party to make a videotape of a number of children with a given disability. The video could cover the range of possible disabilities, and to paint a balanced picture of everyday life, the children could be shown in the community and at home. The distance afforded by a videotape would also

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protect the family making this difficult decision. They would not be under any pressure to make a decision to please anyone but themselves.

Yet, if I were to meet with a family struggling with this decision, there is one thing I would want to say: All new parents look at their tiny babies and wonder if they will be able to rise to the task of caring for them. Parents of children with disabilities are no different. Who can blame them if they question their ability to cope with their children's problems? Yet just as millions of new parents cope with their responsibilities every year, thousands of ordinary couples also rise to the challenge of caring for children with disabilities.

#### It's better to know

At the time of Heidi's diagnosis, I was working in a large office full of women. Many of my coworkers told me how brave they thought I was. No one came right out and said they would have abort-

ed, but I know a lot of them thought it.

It's such a contrast with what we hear now. When people see our bright, happy little girl and find out that we knew about her condition before she was born, they say things like, "What a tragedy it would have been for you to have aborted this beautiful child!"

And Heidi is beautiful. She has a gift for happiness. When we go to the mall, people see her tooling around in her little purple wheelchair, and they smile at her because she's so cute. Then, I frequently see a cloud come over their faces as they realize something must be wrong with her. But the cloud soon gives way to another smile as they realize it doesn't matter, because this child is obviously happy just the way she is.

I do sympathize with women who say that they would never want to be faced with such a decision. I hear women say that knowing ahead of time would ruin the remainder of the pregnancy.

I will admit that my pregnancy was a

very difficult time, but I will always be grateful that when I finally gave birth to my daughter, it was in a setting where she could get the best of care from the moment of her first breath, and that my husband and I were fully prepared to welcome her into our lives with open arms. At the time of a prenatal diagnosis, it may be hard for families to see the value of the opportunity they have been given, but ultimately I believe families and their children benefit most by knowing about problems as early as possible. **EP** 

Alysoun Reichard lives in Kettering, Ohio with her husband, Dave, and daughter Heidi, 5. She writes about issues related to children with disabilities; one of her recent articles, on accessibility, appeared on the op-ed page of the DAYTON DAILY NEWS. This article was adapted from a speech delivered at a genetic counseling symposium held at Brandeis University (Waltham, Mass.) in June 1993.



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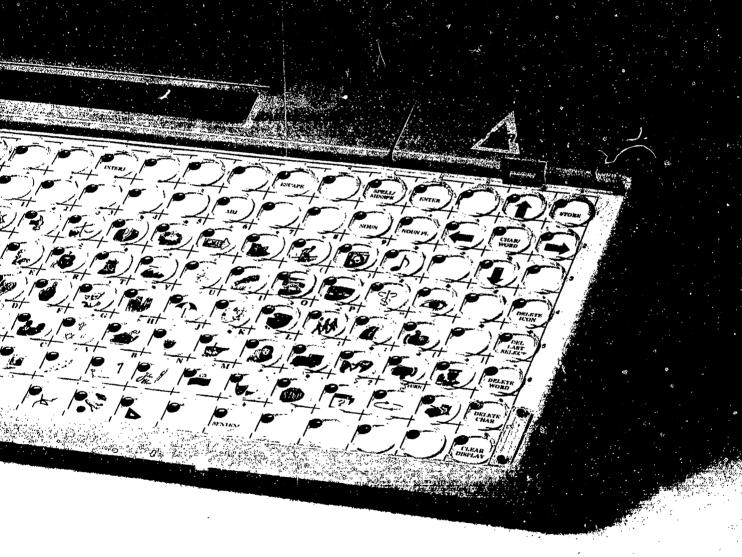
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# A New Twist to "Playing Doctor"

by Rick Rader*

or years, patients have been the comerstone of medical education. Because one can only learn so much from a text-book, "real live people" are used to teach physical signs, procedures, history-taking and physical examinations. Every physician has a story to tell about one or two memorable "teaching patients," who imparted never-to-be-forgotten pearls of wisdom.

I'll never forget my first encounter with a "patient-consultant," as they were known in the London teaching hospital where I trained. I was given 10 minutes to examine this woman's cardiovascular system and come up with a working diagnosis. The woman was quite talkative, especially after she recognized my distinctive New York accent. As I tried to listen to her heart, she babbled on and on about her relatives in Rochester, New York—perhaps I knew them? I couldn't hear a thing through the stethoscope, but I could hear the profes-

* My gratitude to these colleagues whose ongoing interest and contribution to this program has made it possible: Mike Cook, executive director, Orange Grove Center, Chattanooga, Tenn.; Dr. Bob Clark, associate dean & director, University of Tennessee College of Medicine, Chattanooga Unit; Jenny Chase, Amy Khalifa and Nicki McReynolds, special education teachers, Orange Grove Center, Chattanooga, Tenn.; Kelly Bankston, David Lee Williams and Kawanna Williams, patient simulators, Institute of Developmental Medicine, Orange Grove Center, Chattanooga, Tenn.

sor's footsteps coming down the hall, stopping at every cubicle and asking each student to describe their findings. I was starting to panic; I didn't have a clue what this woman's heart was trying to tell me.

Just before the professor got to my cubicle and pulled the curtain back, this little blue-haired lady leaned forward and pulled one rubber stethoscope tip out of my ear. "You won't go wrong with mitral valve prolapse, Yank," she whispered.

At that split second, I turned to the sound of the professor entering the cubicle. "Might it be mitral valve prolapse?" I asked. The professor raised his left thumb like a 1940's Royal Air Force pilot who just heard his Spitfire roar to life. My first experience with a "patient-consultant" was memorable, to say the least.

#### **Patient simulators**

Unfortunately for medical education, the "textbook case" is usually seen only in a textbook. Patients—being people, and cick people at that—are subject to a variety of personalities and individual peculiarities. In addition, diseases announce themselves individually and assume a host of presentations.

These variations of patient and disease have often been cited as obstacles in teaching. How "fair" is it to have three medical students examine three different patients and be tested on their

#### Teaching Docto's to Communicate

I got my Liberator (ail augmentative communication device) in Maich 1994, so I could talk with people. I have been working hard on learning how to use it so visits to the doctor, for one thing, might be more pleasant:

A few years ago, I had to go to the eye doctor, I did not have the Liberator at this time. I had never been to an eye doctor before. My teacher, Nickie McReynolds, prepared me for the visit, but the doctor never even talked to me or asked me a question. That made me frustrated. If he had taken the time, I could have used my "yes" and "no" signs to tell him which lens was better. I don't think the doctor meant to be rude; he just didn't know how to communicate with me. If this doctor had some education about people like me, who use a communication system, or who have signs for "yes" or "no," the visit would have been more pleasant.

Dr. Rader says I can help teach doctors to listen and talk with people who have developmental disabilities. He also said the doctors have to be willing to spend more time with us during a visit. They also should have the opportunity to learn about communication systems. I am willing to give them that opportunity by doing role-playing during lectures, and using the Liberator to tell what is wrong with me.

This is going to take a lot of work on my part, but I am anxious to do it. I hope the medical field is willing to be patient and give me the opportunity to help individuals with disabilities to be better understood.

-David Lee Williams

Patient simulator David Lee Williams watches as Dr. Ric's Rader "acts out" how a physician might examine faint for complaints of abdominal pain. David, who uses augmentative communication, is a particular to "water" a clocker through any manufact plant of complaints and action to the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular and the particular an

findings? To "level the playing field," and to ensure that students are equally exposed to the same clinical scenarios, medical educators created the "standardized" or "simulated" patient.

"Patient simulators" are actors who are trained in the clinical presentation of a particular disease or condition, and hired to play the part of a patient presenting his or her complaints to the medical student. With in-depth understanding of the condition, the actor can direct a student's history-taking to reflect the responses a "real" patient would provide.

Patient simulations have proven to be an effective method for teaching medical history-taking, differential diagnosis, medical communications, medical manners and elicitation of signs and symptoms ("signs" are any objective evidence of a disease as opposed to "symptoms," which are the sensations and complaints reported by the patient).

#### Patient simulators with disabilities

At Chattanooga's Orange Grove Center, a community agency providing educational, medical, residential and vocational services to almost 800 individuals with developmental disabilities, we have taken the concept of the "standardized patient" one step further. We are using individuals with developmental disabilities and mental retardation as patient simulators.

Most medical students and residents—even many seasoned physicians responsible for patient care at a teaching hospital—have had little if any exposure to people with disabilities. Most medical school graduates have seen a 90-minute slide show on dysmorphology—abnormal anatomic development; this slide show is the closest encounter most medical students ever have with developmental disabilities.

Because we believe that physicians need to learn to communicate with their patients who have disabilities, Orange Grove's educational division, the Institute for Developmental Medicine, created the Developmental Disabilities Patient Simulator Program. We believe this is the first undertaking of its kind.

Teachers recommended students for the program on the basis of their personality, disability, health care experience, willingness to participate and ability to learn about and teach various acute (sudden-onset) conditions. Our first challenge was to explain the idea of "playing sick" and to make sure participants understood that this sort of role playing was appropriate only in the teaching setting. Again, teachers helped us to impart this concept—the concepts of "real" and "pretend" are difficult ones. Our next step was to teach participants the script. Although the program is still fairly new, we are pleased with the response we have gotten from both doctors and "patients."

#### "Why don't you take off my jacket?"

We currently have three patient simulators in the program; each one can present a different medical condition. David Lee Williams, 27, who has severe cerebral palsy (spastic and athetoid quadriplegia), presents a "hot appendix." David's role requires an appreciation for the transition from periumbilical (belly button) pain to pain in the lower-right quadrant of the abdomen and the classic "McBurney's point" tenderness,

appearing in the area of the abdomen that corresponds with the normal position of the appendix. David, one of our best standardized patients, communicates solely through augmentative communication, using an electronic, symbol-based communication device mounted on his wheelchair. Accurately diagnosing appendicitis through this unique means of communication provides the clinician with a unique challenge.

Another standardized patient plays the part of an individual



Kelly Bankston, 14, presents an upper arm contracture to an Erlanger Medical Center resident participating in the Developmental Disabilities Patient Simulator Program. In Kelly's first "performance," she suggested that a nervous intern might get a better "feel" for the contracture by first removing her bulky ski jacket.

with a closed head injury from a car accident, resulting in dizziness and blurred vision. Kawanna Williams, 19, has cerebral palsy, mental retardation, microcephaly (smaller-than-average head) and decreased truncal tone (abnormal tension in the main part of her body). Kawanna gives an Academy Award performance as she invites the clinician to compare their conclusions of the neurological exam against Kawanna's "usual abnormal" neurological signs. Kawanna's portrayal of a patient with a head injury presents a unique challenge because—as a result of her disability—even without an injury, she would not demonstrate "normal" neurological signs.

Watching 14-year-old Kelly Bankston invite interns to examine her upper-arm contracture and come up with a diagnosis would put a smile on anyone's face. Kelly has cerebral palsy (spastic quadriplegia), mental retardation and thoracolumbar kyphotic scoliosis (curvature of the spine). During her first "performance," Kelly stopped the nervous new doctor in the middle of her examination and suggested she would get a "better feel" for the problem if she first removed Kelly's bulky ski parka. One can be certain that doctor will never make that mistake again. Kelly's engaging charm provides medical students with the realization that children with developmental disabilities and mental retardation are not just kids with "small-print syndromes" (a reference to their relative importance in medical books), but first and foremost, they are children with dreams, curiosity, humor and frustrations—just like the physicians themselves.

continued on page 38



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Dr. Rick Rader (standing) presents patient simulator Kawanna Williams to attendees at medical grand rounds at Erlanger Medical Center. Kawanna plays the role of a patient with closed head injury resulting from a motor vehicle accident.

#### **Doctors**

like to see the doctors and I like to talk to them. They are nice. They check your braces and they see if your braces are rubbing anywhere. I like them because they make you feel better.

My doctor will see me again in four months. I am excited to see him when he walks in the door.

I'm happy to help doctors learn how to take care of me. I want to teach them how to talk to me. The doctors ask my Uncle Paul all the questions: I want them to ask me because I am the one who knows how I feel:

I want to learn better what to say to the doctors when I make

continued from page 37

This opportunity to introduce neophyte clinicians to real children with developmental disabilities is the "raison d'être" of the program. We are not trying to conduct tutorials in pediatric developmental medicine, but we hope we are expanding the perspectives of each young doctor so he or she will have the confidence, curiosity and consideration to look forward to seeing that child or adult with special needs who will someday come through the office door.

We want the next generation of physicians to appreciate the fact that individuals with developmental disabilities also get the flu, earaches, sprained wrists and cancer. They need to be treated with the same respect, dignity and thoroughness as the other patients in the waiting room. With patient surrogates like David, Kelly and Kawanna we're hoping we can help doctors to not only care *for* these kids, but also to care *about* them. **EP** 

Rick Ra'ler, M.D., a member of Exceptional Parent's Editorial Advisory Board, is the director of the Habilitation Center and The Institute for Developmental Medicine at The Orange Grove Center in Chattanooga, Tennessee. In addition to his post-graduate clinical training in internal medicine, Rick studied medical anthropology and bio-behavioral medicine. Rick's work at Orange Grove involves research into robotics, virtual reality, bioengineering and medical education as applied to individuals with developmental disabilities.

Circle #77

# The Friendly Skies

Transportation no barrier to medical care

rudy and Steven Nelson had raised three children on their farm in Columbia, Missouri, but as the kids began leaving home, they found themselves unprepared to face an "empty nest." The Nelson's fourth child, Caleb, was born in 1987, shortly after the birth of their first grandchild. One year later, Caleb's younger sister, Stephanie, joined the family.

Trudy and Steven were prepared to reacquaint themselves with 2 a.m. feedings, but their son's birth presented additional challenges. Caleb was born with achondroplasia, a form of dwarfism, and had a number of complex physical and medical needs.



Eight-year-old Caleb Nelson (right) visits the cockpit of Mel Potter's six-seater Cessna 414. Because Caleb has had a vertebral fusion in his neck near the brainstem, he can fly only in a pressurized alrcraft like this one; he could not survive the traumatic pressure conditions in some other small planes. Potter (left), an Angel Planes pilot from Wisconsin, is president of Potter & Son, a company that cultivates cranbornies for Ocean Spray.

By the time Caleb was four, the Nelsons had made 25 trips to Baltimore, Maryland to visit medical specialists. Trudy and Steven used credit cards to pay for airline tickets. These transportation costs, added to already substantial medical bills, strained the family's finances. In 1991, they were forced to file for bankruptcy.

But Caleb's medical problems continued. Last summer, faced with the need for another trip to Baltimore, the Nelsons discovered Angel Planes, a national organization of volunteer pilots, based in Las Vegas, Nevada, that could arrange roundtrip transportation for the family.

#### A reason to fly

Angel Planes and other organiz ... ions like it (see sidebar on page 40) were established to ease the financial burden families experience when caring for a child or other family member with special medical needs. These organizations aim to ensure that no individual is denied necessary medical care because a family is unable to pay for transportation. Through volunteer pilot organizations, many children and adults can be flown to distant medical centers for treatment, completely free of charge. Pilots donate their time, expertise, fuel and, usually, their own planes. Some programs also provide seats on commercial flights, using the donated frequent flier miles of business travelers.

Pilot Tracy Winslow has completed 33 Angel Planes flights since 1990. "I get a lot more out of it than I put in," he attests. Winslow, a 34-year employee of Chevron Oil, learned to fly on glider planes while working in Iran. "After retiring," he says, "I didn't know what to do with my pilot's license or four-seater Cessna 172. Angel Planes has given me a reason to fly and something meaningful to do with my retirement. It gives me tremendous personal satisfaction that I could get involved in such a purposeful project at this stage in my life."

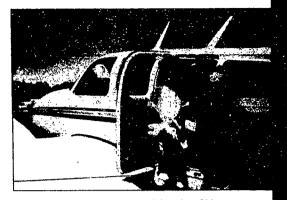
Bill Segal, volunteer pilot and New England flight coordinator for Air Life Line, a similar organization, explains his eight-year involvement with the group in similar terms—"Most pilots like an 'excuse' to fly. Others, like myself, feel blessed to be able to fly and to have this great gift we can offer people who need our help."

#### "Peace of mind"

In May, Caleb underwent his nineteenth surgery—a cranial expansion at Johns Hopkins Medical Center in Baltimore. Because Caleb's skull had stopped expanding, this surgery created the nec-

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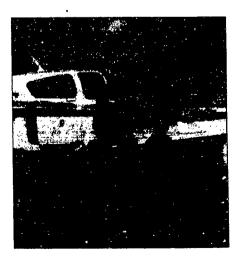
Angel Planes pilot Luther Luttrell (right) of Ohio flew six-year-old Cassie Millis (left) and her family from Erie, Pennsylvania to Little Rock, Arkansas for a medical consultation.

Cassie has tibia hemomelia (one leg shorter than the other). Doctors in her home state had recommended amputation for the shorter leg; Cassie is now undergoing a leg-lengthening procedure in another state.

essary space in his cranial cavity to allow his brain to grow.

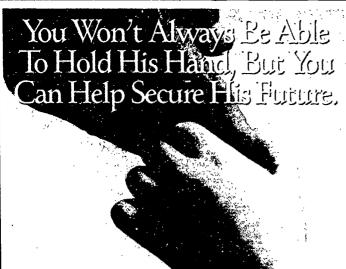
Back home in Columbia, Missouri, Caleb is enjoying his summer and looking forward to entering third grade at Fairview Elementary School. Caleb enjoys bike-riding, tae kwon-do, computer games, outdoor yard work and play-

continued on page 40



Anthony Staley (foreground), 3, of Winnemucca, Nevada, has traveled with his mother and older brother to many out-of-state medical specialists. Air Life Line provided transportation for many of these trips. Anthony has multiple disabilities.





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Circle #31



Pilot Tracy Winslow flew Brandon Moncrief, 4, from his home in Las Vegas, to California's UCLA Medical Center in Santa Monica, Brandon has Crohn's disease.

continued from page 39

ing with his puppy, Jordan.

According to his mom, Caleb considers every trip on a twin engine aircraft a grand adventure. But to Steven and Trudy, these trips are something more. "Angel Planes has been wonderful," Trudy says. "It's hard enough just worrying about how you're going to make it through all the operations and medical expenses. Having someone out there who is willing to take care of the transportation gives parents a real peace of mind." EP

-Michele San Filippo

#### **Volunteer Pilot Organizations**

The following organizations provide free air transportation, to eligible individuals and their families, for appointments with distant medical specialists. Travelers must be medically stable; no medical support is available on these flights. Eligibility is based on financial need; each organization has its own application procedure and criteria for "financial need." A few organizations may also require a medical referral.

Except where noted, flights may originate anywhere within the continental United States. As noted following some listings, certain organizations have limits on the distance of a single flight, but most of these groups will try to help families plan longer trips through relays with other organizations.

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Holland Mi 49423

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#### Air Care Alliance

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Circle #89

# Health Selective Dorsal Rhizotomy

**▼** he term "cerebral palsy" is used to describe many children and adults who have some sort of brain injury ("cerebral") resulting in problems with movement ("palsy"). Since there are different types of cerebral palsy, adjectives describing specific types (for example, "spastic" or "athetoid") usually precede the more general term, cerebral palsy, and describe the way an individual's nervous system and muscles function.

Doctors may also describe people with cerebral palsy in terms of the part of the body primarily affected-for example, diplegia (both legs), hemiplegia (one side of the body) or quadriplegia (arms, legs, face and trunk). They may also classify an individual's disability as being mild, moderate or severe.

Children with spastic diplegia have spasticity (increased muscle tone or tension) that mainly affects their lower extremities. They tend to stand on their toes and bring their legs together in a

crossed-or "scissored"-position. If children with spastic diplegia learn to walk, they typically drag their feet and have limited endurance for walking long distances. They may also have muscle tone problems in the upper parts of their bodies, but these problems will be less severe than in their lower extremities.

In children with spastic quadriplegia, spasticity affects all parts of the body. Spasticity in facial muscles can lead to problems with eating and speech. Spasticity in the trunk can result in seating difficulties. In general, children classified as spastic quadriplegic are less likely than children with spastic diplegia to be able to learn to walk.

Children with spastic diplegia, who are able to walk independently and willing to cooperate with the rigorous physical therapy that will follow the surgery, are considered ideal candidates for selective dorsal rhizotomy (SDR). Since a child's intellectual ability is related to his or her understanding of the procedure and motivation for therapies, clinicians will also consider a child's intellectual ability in weighing the decision to proceed with surgery.

Spasticity and walking

The brain is an incredibly complicated structure. Any explanation of its workings is likely be vastly oversimplified. unable to account for the nuances of human behavior as well as differences between individuals. Furthermore, we still don't know everything about the workings of this complex organ. But with those limitations in mind, let's take a look at brain function with regard to walking, because improving a child's ability to walk is one of the main goals of SDR.

The many parts of the brain are connected by a vast network of nerve fibers. Specific parts of the brain control various body functions. In walking, the part of the brain that controls voluntary leg movements (the motor cortex) initiates "messages" to stimulate the appropriate muscles and to control the

continued on page 42

#### Go For It!

n the summer of 1991, when I was nearly. 13 years old and about to enter the seventh grade, my parents and I decided to find out more about a procedure we had heard about called selective dorsal rhizotomy (SDR). We visited the Spasticity Management Clinic at Children's Hospital and Medical Centers in Seattle, Washington. At first, the doctors weren't sure whether this procedure would be a good one for me because I was doing quite well already; I had only mild spasticity in my legs. But the orthopedic surgeon's opinion was the clincher; he said I could have the surgery if I wanted it.

My parents told me I could make my own decision, and I decided to go for it The surgery was scheduled for February 13, 1992.

I was a little nervous as the date approached, however, we were kept busy with clinic appointments, countless medical tests and a tour of the hospital. We got up at 4 a.m. on the day of surgery. The last thing I remember of that day was one of my doctors

icking with me in the pre-op room. For the next eight days I remained n the hospital, much is a blur. I know I did start some physical theraand teven got back to my schoolwork.



The Ass family--(clockwise from upper left) Sheila, Dave, Ryan, Seun and Dan-cutside their Maple Valley, Washington home, about a year after Flyan's rhizotomy surgery.

because I couldn't fide in a car. My mom and dad took turns staying with me at Children's Village, which is a few blocks from the hospital. During my three weeks there, we went to the hospital for physical therapy twice a day; and, of course there were daily visits to the ever-present hospital schoolroom! For the next two years, I participated in a lot of physical therapy. I started with four times a week after school, with a couple of at-school sessions thrown in for good measure. As time passed, I worked my way down to once a week, then once every two weeks.

I think the results of my surgery were very good. New, I walk with a much more normal gait. Before surgery, I walked with a crouched, turned-in gait. I have before- and after-SDR videos, which really point out the difference. I'm also more agile on my moun-

If I had this decision to make over again, I would choose the rhizotomy. In the future I'm pretty sure I will feel the same.

-Ryan Aas Maple Valley, Washington

Ryan Aas, 16, lives in Maple Valley, Washington with his part



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responses of these muscles. These messages are sent from the brain to the leg muscles through nerve fibers (called motor nerves or motor neurons) that travel from the motor cortex, through two other areas of the brain, and then down the spinal cord. Within the spinal cord, other fibers connect with the motor nerve fibers and relay the messages to the muscles of the legs and feet that are involved in walking. At about the same time, another set of nerve fibers in the legs and feet, known as sensory nerve fibers, send messages back to the brain about muscle tension and sensation (pain, touch and position).

"Muscle tone" refers to the amount of tension (or resistance to movement) in a muscle. When the tone in all muscle groups is balanced, movements are smooth. Too much tone—known as "spasticity" (or sometimes, "hypertonia," a more general term)—causes movements to be stiff and awkward.

Spasticity seems to be the result of brain damage that interferes with messages from the brain, which are intended to stimulate and control muscle tone or tension. In the case of spasticity, however, the control mechanism is impaired, so messages from the brain stimulate the muscles excessively; this causes too much tone, and the resulting movements are stiff, slow and/or jerky.

Of course, the act of walking involves more than these interactions between brain and muscles. Balance is involved—this is regulated by a part of the brain known as the cerebellum: sighted individuals also get useful feedback through vision.

Visual information enters the nervous system through the eves and travels to the part of the brain involved in seeing (the occipital lobe). The occipital lobe is interconnected in complex ways with the other parts of the brain involved in walking. In fact, walking, like many other "ordinary" activities, involves the coordination of an intricate system that allows many parts of the body to "communicate" with each other via the brain.

#### When to consider SDR

SDR is not usually performed until a child is at least three years old-and more commonly, seven years old or older. In fact, clinicians often wait until a child is three years old before identifying the type and severity of his or her cerebral palsy. This is because the brain cells and the connections in the brain may change as the child matures.

Even when a child's diagnosis is clear, it can be difficult to predict the progress an individual child might make with nonsurgical therapies. (For more about non-surgical alternatives to SDR, see Ask the Doctor; page 46.) However, children with cerebral palsy and a resulting delay in the development of "motor skills," usually begin to walk by about age seven if they are going to learn to walk. Also, a seven-year-old child with at least average intellectual abilities will be able understand the purpose of surgery, and will probably be motivated to cooperate with the extensive physical therapy that follows.

#### **Evaluating "Success"**

t's been seven years since our son, Sean, now 12, had his rhizotomy. As I reflect on Sean's surgery, his recuperation and the ways he has changed since that time, I recognize that I still have very ambivalent feelings about the outcome.

The team of surgeons and therapists working with us did a thorough job of evaluating, screening and educating us about the procedure. I was very careful not to expect too much from the surgery. Sean was not a "walker"—he was not even a "sitter"—so ambulation of any kind was not a goal. His spasticity was so strong, however, that it was often difficult just to dress him, hold him or even get him into his wheelchair. I thought the rhizotomy would make

so ne of those things easier, and the surgeons concurred. The post-surgery plan

was for Sean—and therefore me, too-to remain in the hospital for three to four weeks, primarily to facilitate the two to three hours of daily therapy considered essential to the success of the surgery. Needless to say, this was very stressful for the whole family. Following the surgery, Sean was writhing in pain; even the intravenous morphine

cessful at making him more comfortable. A couple of days later Sean developed double pneumonia. Though I was a veteran of surgeries and hospitalizations with Sean, my heart was breaking. just hoped it would all be worth it.

Time passed as we faithfully dedicated ourselves to the many hours of therapy. Months later, after comparing pre- and postsurgery evaluations and videotapes, the team pronounced Sean's rhizotomy "a success." Five years down the road, I'm not so sure. Before the surgery, Sean was able to use his extension to help in weight-bearing for transfers; now, he can't. I see no measurable gains in functional skill areas. His fine motor coordinationneeded for feeding and typing—has not improved; nor does he have improved balance or strength for sitting, rolling or "combat crawling." Yes, his spasticity has decreased, and his legs "scissor" less, but even that improvement was most noticeable after the hip surgery he had a few years after the rhizotomy.

This brings me to my basic dilemma in evaluating the "success" or "failure" of Sean's rhizotomy. We will never know what his course of development would have been without the procedure, so we can't say for sure whether his improved speech, for example, was a result of, or totally unrelated to, the rhizotomy. Would his extension and tone be worse today without the surgery? Maybe... maybe not. Would he have had more difficulties with his hips had he not had the surgery? Who knows?

As parents of children with disabilities, we make our choices based on what we believe will lead to a better life for our kids. Sometimes this means saying "yes" to surgery even though we know it will mean another trauma they and we don't need Sometimes we say "no" to interventions, knowing we need time to regroup, reevaluate and try to stay whole. I do know that Sean is happier and healthier today than he ever has been. rhizotomy contributed to:



Chambers family—(from left)

The evaluation process

Prior to surgery, the child should be evaluated by the team of medical professionals who will be coordinating his or her care, before, during and after surgery. The team will include a neurosurgeon (a surgeon who operates on the brain and nervous system), physical and occupational therapists, other clinical specialists and, often, the child's pediatrician. These team members, at least some of whom should have considerable knowledge about the growth and development of children with cerebral palsy, can make fairly good predictions about the likely outcomes of various surgical and non-surgical procedures. One key task for the team is to make sure that the child has spasticity rather than other types of movement limitations, such as dystonia (slow, rhythmic, twisting movements of the trunk, or of an arm or leg). Some children with quadriplegic cerebral palsy have both spasticity and dystonia, and may not be candidates for SDR.

The team also needs to measure the child's abilities to move his or her arms and legs and to perform various tasks such as sitting, walking and self-help activities. This measurement of the child's "functional abilities" before surgery can serve as a basis of comparison with his or her abilities after surgery.

The evaluation process is also the time when the team, the parents and the child can learn about the surgery itself; how the child is likely to feel before, during and after; and details of the intensive therapy that will follow SDR. In addition, it is

continued on page 44

have to agree with Ill that we don't really know the usefulness of rhizotomy in children with cerebral palsy. Currently, several large studies are evaluating its effect, but it is still an unproved procedure. One of the difficulties in studying a new procedure is that we don't have two equal groups of children to compare. Every child with cerebral palsy has a unique" cerebral palsy.

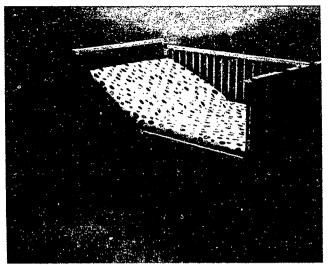
I don't know Sean's rhizotomy was a success, but comparing Sean to the hundreds of children with cerebral palsy I have cared for in my profession as a pediatric orthopedic surgeon, I believe his spasticity was decreased by the rhizotomy. Although he has had several later orthopedic surgeries, it is my impression that by lowering his spasticity, we have eliminated much of his posturing and extension. Current studies are showing that some children who have had rhizotomy surgery face long-term problems with scoliosis (curvature of the spine) and lordosis (sway back), so we're not looking forward to that.

Was rhizotomy worth it for our son, Sean? Can I recommend the surgery to my patients? These are hard questions to answer. That's why medicine is as much art as science.

—Hank Chambers

Jill Chambers is an advocate for her son, Sean, and other children with disabilities in San Diego. She is very involved in community activities. Hank Chambers, M.D., is a pediatric orthopedic surgeon at San Diego Children's Hospital and the University of California at San Diego. He also serves as the Chairman of the Advocacy and Parent/Consumer Relation Committee of the Amerikan Academy of Cerebral Palsy and Developmental McCiline. Hank and Jill live in San Diggo Cal

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essential that everyone discuss their expectations about the results. Some parents—and children—may have expectations that exceed those of the clinical team, who base their expectations on the results they have seen in similar children.

The team also needs to discuss the surgery's cost and its potential risks. In the United States, SDR and the intensive therapy that follows will cost \$30,000 to \$50,000. Some health insurance plans cover all or some of the costs involved. In Canada, the national health plan covers all costs.

Surgery always involves some risk—infection, unexpected bleeding or side effects of anesthesia. In SDR, there is the additional risk that the wrong nerves or too many nerves will be cut; this can cause new problems or further complications. Even when the appropriate nerves are cut, some children experience sensory abnormalities, such as numbness or tingling in some areas of the body. Sometimes, SDR seems to cause permanent weakness or reduced function.

#### The surgery

Before surgery, a child receives a general anesthesia, which makes him or her unconscious for the entire procedure. An anesthesiologist will monitor the child's bodily functions during the surgery.

The neurosurgeon begins by creating several small openings in the protective bone around the spinal column at different levels. Using a microscope, the surgeon can now see the motor nerve fibers, which originated in the brain, and exit the spinal cord, at different levels, to control movements of muscles and tendons in the hips, legs, knees, ankles and feet. The surgeon also has access to the sensory nerve fibers that relay messages from the muscles and tendons, through the spinal cord, to the brain.

To reduce spasticity, the neurosurgeon will cut some of the tiny rootlets that make up each sensory nerve fiber. Rootlets of motor nerves will not be cut, because this would prevent the muscles from receiving messages from the brain, leaving them with no tone—soft and unresponsive. It is unclear why cutting sensory nerve rootlets decreases spasticity, but doctors believe that decreasing the number of messages being sent from the muscles to the brain causes the muscle tone control system to work more effectively.

The surgeon goes through a careful and time-consuming process of applying electrical stimulation to the sensory nerve rootlets—one-by-one. By watching the way the muscle tone responds to this electrical stimulation, the surgeon can determine which rootlets seem to be associated with increased spasticity; those rootlets are cut.

The surgical procedure may take four to eight hours, even as long as 12 hours. It is a lengthy procedure because the team must take the time to be certain they are in the correct areas of the spinal cord. Then they must check each tiny sensory nerve rootlet to decide whether or not to cut it.

#### After the surgery

For the first three or four days after the operation, the child is confined to bed, lying on his or her stomach. The child will be sleepy and feel weak, especially in his or her legs. The child will have a long bandage on his or her back and is likely to experience considerable pain and discomfort. Doctors will prescribe pain medications. The child may feel nauseous or vomit; these problems are also treated by medication.

About 10 days after surgery, the stitches will be taken out of the child's back. After that, he or she will probably be able to be transported in a wheelchair.

In general, for the first four weeks, the child will receive physical therapy for up to two hours a day, five days a week. If the child has upper limb difficulties, he or she will also receive regular occupational therapy.

The child will be able to start physical therapy while still in bed, four to five days after surgery. However, for three to four weeks, he or she will continue to be weak and unable to tolerate sudden movements. As a result, the child will not be able to travel, and usually stays in a rehabilitation center, or in (or near) the hospital where the intensive therapy program will take place.

After the first month, the child can return home and attend school. Physical therapy—usually one hour a day, four or five days a week—will continue for five months. Then the child will continue physical therapy on a more typical schedule of one to three hours a week.

Over a period of three to six months, the child can be expected to gradually recover the abilities he or she had before surgery, and then begin to improve on these abilities. Some children make gains over their pre-surgery levels just three months after surgery. However, these gains may not last; some children do not seem to maintain their improved functional abilities over a period of years, even though their spasticity remains decreased.

#### Results?

Not all children improve after SDR. Some even lose ground. Although clinicians know that children with spastic diplegia are more likely to improve than children with spastic quadriplegia, they cannot predict which individual children will improve.

When improvement occurs, it may be different for each child. Following SDR, children with spastic diplegia may be able to stand with their feet flat on the floor; they may: lso make gains in walking, climbing stairs or self-care tasks. Some people even report improvement in skills that include upper body movements—probably related to an improvement in overall balance and stability. Children with spastic quadriplegia may improve in sitting or in their ability to transfer from one seated position to another. They may also improve in relf-care skills and be less dependent on the assistance of others.

#### Cautions

SDR usually decreases spasticity. However, functional abilities (abilities to perform day-to-day tasks) do not always improve, even with less spasticity.

Some experts believe that improvements noted in some children following SDR may not result from the surgery. Rather, these improvements may be the result of the intensive therapy following the surgery and/or other factors such as developmental changes (changes that would have taken place anyway, as the

child matured) or expectations of improvement that lead the parents and/or the child to have increased motivation and to make greater efforts to meet therapeutic goals.

When children do not receive intensive physical therapy following SDR, they are much less likely to improve. This seems to demonstrate that the therapy is essential, however, it does not prove the surgery is necessary. Some experts believe that less complicated procedures, such as certain orthopedic surgeries, can bring about similar improvements in standing or walking.

A recent fact sheet on SDR from the United Cerebral Palsy Research and Education Foundation states, "...there is still debate as to whether the long-term benefits of the procedure justify the risks, cost and expenditure of family resources. At this time, the available data indicate that SDR decreases muscle tone (spasticity), however, there are inadequate data to support or reject the usefulness of selective rhizotomy to improve long-term function..."

#### Research in progress

Three current research studies are attempting to determine whether SDR is critical to functional improvements. These studies will compare the improvement between children who receive *both* SDR and the intensive therapy, and similar children who receive the intensive therapy *without* the surgery. The results of these important research projects will be report-

ed over the next two years.

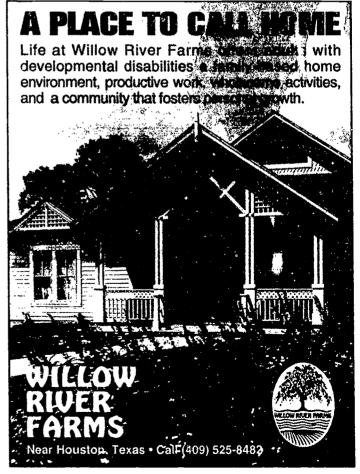
Other current research shows that the use of small amounts of botulinum toxin may decrease the spasticity of some muscles for as long as four to six months. A medication, baclofen, can be safely administered into the parallel fluid. This research offers hope that spasticity reduction may someday become possible without surgery. **EP**—S.D.K.

The following medical experts contributed their experience and wisdom to this article. All are members of the American Academy for Cerebral Palsy and Developmental Medicine.

- MURRAY GOLDSTEIN, D.O., Medical Director, United Cerebral Palsy Research & Education Foundation, Washington, DC.
- JOHN F. McLaughlin, M.D., Professor of Pediatrics, University of Washington School of Medicine; Director, Neurodevelopmental Program, Children's Hospital and Medical Center, Seattle, WA; Principal Investigator, "Selective Dorsal Rhizotomy: Effects in Cerebral Palsy," a five-year research study funded by the National Institute of Neurologic Disease and Stroke of the National Institutes of Health.
- PETER ROSENBAUM, M.D., Professor of Pediatrics, Faculty of Health Sciences, McMaster University; Investigator, Neurodevelopmental Clinical Research Unit, Chedoke-McMaster Hospitals, Hamilton, ON, Canada; "National Health Scientist," an award to outstanding researchers funded by Health Canada.



Circle #11





Circle #91

# ASK THE DOCTOR

by David Hirsch, M.D.

### Rhizotomy?

Our six-year-old son has a form of cerebral palsy called spastic diplegia; that is, he has severe increased muscle tone (spasticity) in his lower extremities. He has mild developmental delays, but no other neurological problems. He does not have contractures (abnormal shortening of a muscle due to increased tone, usually resulting in joints remaining in a flexed position), and he has not required any orthopedic procedures so far.

He is walking with the help of a walker, but it is a considerable effort. In fact, it frustrates him to the point where he would rather not use the walker. He receives physical and occupational therapies, which have been helpful.

Our pediatrician has suggested that he be evaluated for a rhizotomy procedure. I have heard good and bad things about this surgery. What do you think? Are there any other options available?

The purpose of any therapy or A surgical procedure for spasticity should be to improve the quality of life and self care. Selective dorsal rhizotomy (SDR) is a surgical procedure that has been used for many years to relieve spasticity of the lower extremities. In the last 15 years or so, there has been improvement in the technique, leading to more successful results. Increasingly, doctors are giving more thought to selecting the best candidates for the procedure, so the surgery will be done only on children who seem likely to benefit. This has also resulted in better overall results.

Based on your son's lack of other neurological or orthopedic complications, along with his and your motivation, your son may be a good candidate to be considered for SDR.

If the procedure is done by an experienced team of physicians and therapists, and considerable care is taken from candidate selection through follow-up, few complications typically occur. However, short-term problems with pain, urinary retention and sensory loss (from irritation or damage to the sensory nerve roots during the procedure) are not uncommon. Some recent studies also suggest the possibility of later complications such as decreasing range of muscle movement and hip dislocation; a small percentage of SDR patients will need additional orthopedic procedures sometime later.

My patients who have had SDR followed by intensive physical therapy, typically have had good results in terms of improvement in motor and self-help activities such as walking, toileting and transferring position.

#### Other treatment options

· Physical therapy-Aggressive stretching of tight muscles at involved joints is another option for the treatment of spastic diplegia. The goal is to increase range of motion and subsequent mobility. As the child progresses, his or her physical therapy will focus on muscle strengthening, gait training (improving the walking pattern) and, when appropriate, the use of adaptive equipment.

In range of motion exercises, done by or under the direction of a physical therapist, an adult moves one of the child's limbs, usually across a joint, in a repetitious and careful manner. Done properly, and often enough, range of motion procedures can significantly reduce the occurrence of complications such as contractures. Range of motion procedures are usually done in conjunction with the following treatment options:

- Serial casting-In serial casting, casts are used to reposition a joint or extremity. The first cast applied is intended to move the joint a certain amount. It is left on for a period of time-usually one to four weeks. Then, that cast is removed, and another cast-which moves the joint or extremity even closer to the normal position—is applied. This continues until the position of the joint or extremity has been altered.
- Neuromuscular electrical stimulation (NMES) is a newer procedure that has been used in conjunction with an aggressive, task-oriented physical therapy program. In NMES, very weak

electrical currents are used to stimulate certain muscles. Initial results on some patients show promising results. but more study needs to be done.

- Orthopedic procedures for the treatment of spastic cerebral palsy have been done for some time and are well established. For example, children with cerebral palsy may walk on their toes because of tight heel cords. When less invasive procedures such as splinting, bracing and/or physical therapy have not relieved this problem, a surgical procedure may be done to lengthen the tendons in the child's heels. More recently, SDR and orthopedic procedures have been used to compliment each other i. The treatment of spastic cerebral palsy.
- Pharmacological treatment (medications) may also be helpful. Most commonly used medications consist of benzodiazepines such Valium and Tranxene. Commonly used to treat anxiety, they also have the effect of decreasing muscle tone.

Dantrolene, a skeletal muscle relaxant, has a slightly different method of action. At this point, it has been used only in adults; like the benzodiazepines, it may cause excessive sedation.

One other medication, called Lioresal (baclofen), may be taken orally or intrathecally (administered directly around the appropriate area of the spinal cord). Researchers are currently studying the effectiveness of using this drug in this manner for the treatment of spastic cerebral palsy. **EP** 

In this column, David Hirsch, M.D., a pediatrician and member of the Exceptional Parent's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and

chronic illnesses. Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mentions of specific products or medications illustrates suggestions; he is not endorsing

any specific products. Send questions to: Ask the Doctor, Exceptional Parent, 209 Harvard Street. Suite 303, Brockline, MA 02146-5005, (617) 730-8742 (Fax).



# Health

# This Doctor's Point of View

Knowledge and emotion go hand-in-hand

In December 1994, I spoke to a group of physicians at the Schneider Children's Hospital of the Long Island Jewish Medical Center about communicating difficult news to parents. After the talk, Arthur Weber, an orthopedic spinal surgeon, approached me to "confess" that he sometimes cried with parents about a child's complicated medical needs. A bit embarrassed, he joked that his physical size and manner made everyone think he was a "tough guy." Dr. Weber told me he had never discussed these emotional reactions with his colleagues or students.

I encouraged Dr. Weber to share his experiences with the readers of Exceptional Parent. In all the years I have been teaching professionals about communicating with parents, no one had ever asked me about professionals sharing their sadness through crying. I felt that both parents and professionals needed to hear about physicians' feelings.

At the end of June, Dr. Weber faxed a first draft of an essay. I called to tell him we wanted to publish it, and, because he had not directly addressed crying, I asked him to write a few more paragraphs.

On the evening of July 3, Dr. Weber operated on a patient until late in the evening. The next day, Dr. Weber suffered a fatal heart attack. Parts of this uninished essay were read at his funeral. Dr. Weber had spoken to his friends and colleagues about his essay—he'd described looking forward to its publication with pride. Sadly, Dr. Weber will not be able to participate in the discussions his essay will stimulate. But these discussions will serve to honor his memory.

—S.D.K.

#### by Arthur H. Weber

y life as a doctor began with an internship on the cold windswept shores of the Bay of Fundy, in the city of St. John's, New Brunswick.

As inexperienced as I was, I loved those first few months. I spent much of my time caring for adults. Most injuries were repaired and most of the sick were either cured or went on to live out life's natural cycle. Although it is sad when older people die, it usually is not surprising, and can sometimes be a welcome relief from continued suffering. And besides, I was a witness to beginnings as well as endings. I delivered many babies; my life was full of flowers, chocolates and parties. Medicine was wonderful—it was everything I had expected it would be.

The third rotation of my internship involved training in pediatrics. I began working with children who had many different illnesses—everything from severe fever and upper respiratory infection to gastrointestinal illnesses. I got their flues, sometimes their fevers and even their diarrhea. But I was healthy and strong, and I could still function as a doctor. After a while, I became immune to their

contagious illnesses.

During the next few weeks, I was exposed to two different categories of children—those with congenital disorders, who had lifelong structural problems, and those with life-threatening problems, such as cancer and leukemia. These



This patient (left), a young man with Down syndrome, wanted to give surgeon Arthur Weber a kiss.

children, especially those in the latter category, left indelible impressions that have molded my medical career.

Children with terminal illnesses were

brought to the hospital to live out the last days of their lives. The hospital took basic measures to make these days more bearable—we cooled their fevers, replaced their fluids, fed them and rendered the necessary supportive care. These tasks were easy to learn. The harder lessons came not from doctors or nurses but from parents. Parents with no medical knowledge showed an instinctual caring that went beyond medical treatment; I discovered there was no substitute for their comforting caresses and voices.

Families shared their suffering with dignity. When a child became weaker and more feverish, the bonds between child and parent tightened—almost as if those bonds could keep the inevitable at bay. Parents held their children in their arms as long as they could, walking back and forth along the long, dimly lit corridors of the hospital.

The frustration I felt as a physician was agonizing; I could not intervene in this suffering. My helplessness angered me, but I learned a great deal about love, hope and human interaction.

The days of that third rotation are now far behind me, but its lessons remain important. As a spinal surgeon I am often called upon to deal with

continued on page 48



contoured from page 47

children who have multiple disabilities. The most challenging are the children who require constant, unrelenting care. Their parents ask me to help them make their children's lives an iota better.

Seemingly small changes, such as helping children sit up independently, can be quite

significant. Sitting up on their own, children eat and digest their foods better. They see the world differently, if they can see. Their hips do not dislocate. Their incontinence becomes more manageable. Their pressure sores become rare. Their breathing and pulmonary care improve, and their persistent upper respiratory infections decrease.

I used to wonder why the parents of these children didn't just quit, let go, stop treatment. Then I became a parent myself, and I began to understand



Dr. Arthur Weber with patient Barbara Rupp. Barbara, 12, has undergone 14 spinal surgeries.

things not only academically, but within my soul. As a physician I had been knowledgeable; as a parent, I gained understanding.

This understanding has often proved crucial. For instance, spinal surgery and recovery are arduous, so I do everything I can to assist families as they make decisions

about surgical procedures. I help them consider whether the benefit of treatment will outweigh the risks and difficulties. I help them ask the necessary questions: Does the child really need this operation? What would be the consequences of doing nothing? What are the chances of bringing this child through from surgery to recovery? Hours of reflection and planning may go into each case as we try to foresee potential problems and head them off before they occur

I never operate without exploring all

possible consequences of surgery. As a surgeon, I actively live through each operation, and do not feel well until my patient does. Being entrusted with a child's care is a special mission—a mission on which I have been grateful for the company of the children's exceptional parents.

Arthur H. Weber lived in Mill Neck, New York with his wife of 19 years, Valerie Weber, a physical therapist. Dr. Weber, a physician and surgeon, specialized in spinal disorders, reconstructive spine surgery and spinal trauma. In addition to his private practice, he was an assistant clinical professor at the Albert Einstein College of Medizine. He also taught at the State University at Stony Brook, New York Hospital/Cornell Medical Center and Long Island Jewish Medical Center: He published in several medical journals and was a diplomat of the American Board of Orthopedic Surgery. He suffered a fatal heart attack on July 4, 1995. He was 52.

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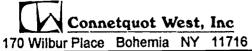
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# **Understanding Enuresis**

he development of bladder control is a process that typically occurs over several years. Bladder control development varies quite normally in individual children. However, between one and two years, children usually become gradually aware of the sensation of a full bladder. By three years of age, most children are able to tense the muscles of the pelvic floor and "hold" urine for prolonged periods.

Our culture places much attention on how and when a child gains bladder and bowel control. It is not surprising, therefore, that family distress often results when this control does not occur. Daytime wetting (diurnal enuresis) and bedwetting (nocturnal enuresis) are quite common. "Enuresis" can be defined as the "involuntary discharge of urine by day or night (or both), in a child aged five years or older, in the absence of congenital or acquired defects of the nervous system or urinary tract." If a child has never been dry for a significant period, he or she is considered to have "primary enuresis." "Secondary enuresis" refers to loss of bladder control in a child who is at least four years old, after he or she has been dry for a significant period.

#### Nocturnal enuresis: Who is affected?

Nocturnal enuresis has been defined as ranging from one wet episode a month to seven or more a week. Based on an average of two wet nights per week, it is estimated that the number of children affected are: 15–20 percent of five-year-olds, seven percent of seven-year-olds, five percent of 10-year-olds, two to three percent of 12- to 14-year-olds and one to two percent of 15-year-olds. In older age groups, enuresis can be extremely stressful and socially disruptive. A person's ability to make changes in his or her life, such as starting college or getting married, is often inhibited by enuresis.

#### **Contributing factors**

A number of factors may contribute to enuresis. For example, genetic factors may play a role. A family history of enuresis is quite common, and one study found that identical twins were almost twice as likely as non-identical twins to both have nocturnal enuresis.

In children younger than five, delayed maturation may contribute to slower development of bladder control. A stressful life event can also contribute to the occurrence of enuresis. A small functional bladder capacity is often another contributing factor.

Constipation and sleep apnea are physical problems that may contribute to nocturnal enuresis. Chronic constipation can irritate the bladder, which results in frequent urination.

Sleep apnea—periods of non-breathing during sleep—decreases oxygen levels. This may make a child less responsive to the sensation of a full bludder, and less likely to wake up when he or she needs to urinate.

The presence of a urinary tract infection (UTI) should be ruled out before

beginning any treatment for enuresis. Approximately five percent of girls and two to three percent of boys will have a UTI at some point during childhood.

#### Dispelling myths

Enuresis can have a damaging effect on parent-child relationships and a child's relationships with peers. These damaged relationships may further lessen a child's self-esteem. This makes it especially important to dispel myths about the causes and prevention of enuresis.

Contrary to some misguided beliefs, bedwetting is not deliberate or controllable. Restricting fluids will not help a child develop bladder control. Shaming and rejecting the child does not stop bedwetting, but it does increase the child's anxiety and lower self-esteem.

#### Medication

Medication is one treatment option. According to the Enuresis Resource and Information Centre (United Kingdom), two main types of drugs are prescribed for bedwetting—antidiuretic hormone (ADH) and tricyclic antidepressants.

Studies have shown that some children who wet the bed produce less ADH than children who do not wet the bed. ADH is available by prescription in the form of Desmopressin, a nasal spray. This medication decreases the amount of urine output at night. Desmopressin has an almost immediate effect lasting five to nine hours, and has a success rate of approximately 70 percent.

Tricyclic antidepressants, such as imipramine (Tofranil), are thought to relax the bladder (detrussor) muscles, allowing the bladder to hold more fluid before contracting. Antidepressant drugs can take up to a week to take effect; possible side effects include irritability, loss of appetite, headaches and constipation. Like all medications, drugs given for enuresis should be stored safely out of the reach of children.

If your child has enuresis, your physician can tell you about the most recent medications available, and how they might be used in your child's case. It is important to remember that medications alleviate—rather than cure—nocturnal enuresis. Once medication is stopped, bedwetting often recurs. **EP** 

This article was adapted from two articles previously published in The Informer, the newsletter of The Simon Foundation for Continence. For a free information packet, contact The Simon Foundation, P.O. Box 835, Wilmette, IL 60091; (800) 237-4666, (708) 864-9758 (fax).

ENURESIS

Enuresis: A Guide to the Treatment of Enuresis for Professionals is now available exclusively through the Simon Foundation for Continence. This guide is edited by Penny Dosson, R.N., executive director of the Enuresis Resource and Information Centre in England. The guide includes chapters on assessment, treatment methods, choosing a treatment program, dealing with relapse and advising the older child and adult. Although written for the professional, the readable style makes this book understandable and useful to the layperson as well. The book costs \$24.95 and can be ordered directly from the Simon Foundation, P.O. Box 835, Wirnette, IL 60091.



EXCEPTIONAL PARENT / AUGUST 1995

# MOST PARENTS OF BED WETTERS THINK THERE IS VERY LITTLE THEY CAN DO TO HELP.

Some 3 million children, 10% of all kids between 5 and 10, wet the bcd twice a week or more. If your child is in school, chances are at least two of his classmates are in the same leaky boat. No child should ever feel alone with this problem. But, of course, they do

The good news: More is known than ever before that can help. Once, the only sure cure was time. 99.9% of our children leave this problem in the dust as they grow. And now there are some new ways to give time a hand.

#### THE BEST BEGINNING

For starters, pediatricians know a lot more about the causes of "enuresis" (that's the official medical name for it) than they used to.

Doctors today deal with this problem all the time. They have new techniques and sometimes medicines that can help manage bed-wetting, if not eliminate it altogether.

And now (finally!), there are pants you can buy that can make a real difference at your house, every night and every morning. Your child will still wet. He can't help it. But from now on, that doesn't have to mean he has to wet the bed.

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people have done everything possible to make these absorbent underpants respect our kids like the grown-ups they soon will be.

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GoodNites are not a miracle, but there's nothing like them. They help families keep bed-wetting in perspective. They help make dry mornings, in crisp clean sheets, routine. And make sleep-overs and other normal, healthy everyday kid things routine, too. The way they should be.

#### THE GOODNITES GUIDES

GoodNites underpants were developed with the help of pediatricians and other childhood specialists. You'll find much of their good advice in these little hooklets. One is written for parents. The other is for your child. For copies, please send \$1 for postage and handling to: GoodNites Guides, P.O. Box 1165, Maple Plain, MN 55592.



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# **Food for Thought**

Helping your child on a special diet eat right

by Marsha Magol

ersuading a child to eat different and nutritious foods. whether or not the child has special health care needs, can be an exhausting and frustrating experience. However, you can help your child develop positive attitudes about nutritious foods.

Children learn best by example. Remember, your child wants to be like you. If the child sees you eating more salads, fruits and vegetables, he or she may want to do the same.

#### Listening to our kids

My bright, six-year-old son, Jeffrey, has phenylketonuria (PKU), a metabolic disease that requires him to follow a low-protein diet regimen. This means plenty of substitutions when his friends may be eating "funner" food. When a special diet is a life-long requirement, it is important that children develop a sense of responsibility for what they eat. At the same time, it is important to allow them to express their feelings about the diet. We can learn a lot by listening carefully.

For example, Jeffrey recently said to me, "Mom, I really liked the 'peanut butter' (actually a low-protein substitute) and jelly sandwich you put in my lunch box today." I realized that this sandwich was more than just a tasty lunch. I knew that it also boosted Jeffrey's self-esteem to be able to eat food that looked similar to that of his peers.

Another time Jeffrey came home from school, sad and dragging, and said emphatically, "I don't like this diet!" Together, we figured out he was unhappy because he couldn't eat a ham-

> burger. Regular hamburgers had too much protein, but tegether we came up with an acceptable substitute-low-protein mushroom burgers. As parents, we have to follow medical advice, but we can still learn to listen to our children and creatively man

age their diets. Children appreciate being able to express their feelings openly and having their needs treated respectfully.

#### A voice and a choice

Parents can reinforce a sense of responsibility in children by giving them a voice and a choice in matters that affect them. Severely restricting your child without explanation can lead to immaturity and rebellion. Children will accept "rules" more readily when explanations are given. Although health conditions may limit some options, we can help children accept inevitable choices gracefully.

Parents can involve young children in food choices by talking about them. For example, a two-year-old can decide whether he wants a half glass of milk or a full glass. A fouryear-old can be asked if he wants an apple or an orange, or whether he wants his bread toasted or plain.

Children can be deliberately presented with many situations in which they have to make choices and are given chances to succeed. We can creatively select the situations and let children make the choices. This sends a clear message that children are not just recipients of "orders," but participants in decisions that affect them.

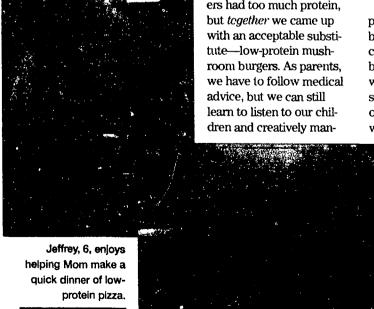
For example, when Jeffrey was very young, I always kept frozen low-protein bread and pancakes in Ziploc bags in the freezer, on a low shelf at Jeffrey's eye level. I would let him choose between brend or a pancake by responding verbally, by pointing or by actually getting it out himself. This made him feel that he was "in charge," and was a very small step toward dietary self-management in the future.

I also kept a variety of fresh fruit and vegetables in the lower part of the refrigerator so Jeffrey could see the choices between tangerines, grapes, plums and other fruits, or the choices between lettuce, carrots, celery, tomatoes or cucumbers in the vegetable crisper. The pantry was set up the same way with small cans of fruits and vegetables on the lower shelf so I could ask Jeffrey, "Do you want carrots or green beans?" or "Do you want Mott's peaches or a Strawberry Fruit Pak?" He would go to the drawer where the measuring cups are kept and

hold a cup up to the item he wanted.

Introducing new foods may take some effort. However, you will be rewarded quickly when you see your young child making the right choices from a smorgasbord of food. You can help your child develop tastes and preferences that last a lifetime. **EP** 

This article was adapted from two pieces by Marsha Magol that first appeared in National PKU News. Marsha is a regular contributor to this publication. She and her husband have one son, Jeffrey, 6. They live in Tampa, Florida, where Marsha works for GTE.



## MEDIA

Irene Pollin, author of TAKING CHARGE: OVERCOMING THE CHALLENGES OF LONG-TERM ILLNESS, is a parent and psychiatric social worker. In dealing with her children's illnesses, Pollin became aware that professionals receive scant training to help individuals and families cope with long-term effects of chronic illness or disability. Neither mental health nor medical specialists provided the support she and her husband needed. After the loss of two of her own children, Pollin returned to school for training as a psychiatric social worker.

Although TAKING CHARGE: OVERCOMING THE CHALLENGES OF LONG-TERM ILLNESS was written specifically for individuals with long-term illnesses, every chapter is filled with powerful information and helpful support for parents and other family members. For example, this excerpt, which discusses the doctor-patient relationship, can also be applied to the doctor-parent relationship. TAKING CHARGE is available from Exceptional Parent Library (800/535-1910).

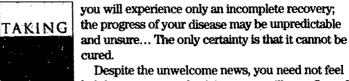
Forging an Effective Doctor-Patient Partnership

Forging effective doctor-patient partnerships may be one of the most important "take charge" tools at your disposal... Your relationship with your physician will affect your emotional and personal well-being, not just your physical condition. Your level of stress will decrease if you trust, respect and feel comfortable with your physician, if you believe that he cares about you and will be responsive to you. Indeed, your interactions with your doctor will influence the quality of your daily activities and can affect life-and-death decisions...

You can create supportive relationships with your physicians. When you establish the boundaries of your partnership early on, your doctor will be concerned with your feelings, not just your physical condition. That's important because your emotional comfort level with your doctor can affect how you respond to prescribed treatments. But first you must understand how your chronic condition differs from other medical problems you might have encountered in the past, and how your care will diverge too...

Your first encounters with the specialist may be marked by frustration. For example, she may be unable to reach a clear diagnosis or may accurately analyze the problem only after exhaustive tests. Indeed, the waiting period between your first appointment with the specialist and a definitive diagnosis may seem like a special kind of purgatory. Your anxiety will most likely heighten as you undergo physically unpleasant or even risky tests. You may exhaust yourself from the constant worrying but still have to pay the mounting bills and fill out endless insurance forms.

Finally, your doctor will arrive at a definitive diagnosis. You may feel somewhat relieved that you now have something concrete to deal with, but the news isn't all that good. The specialist, for example, may have few options to offer as treatments. She may also explain that



Despite the unwelcome news, you need not feel helpless with your physician or your illness. One of the best ways to take charge of your disease is to know exactly what you're dealing with. Unless you

know what your disease is, how it manifests itself, its likely prognosis and how the treatments may or may not help you, you cannot make a realistic evaluation of your medical condition or the course of action you should pursue. Indeed, unless you are fully informed, you cannot be responsible and in control of your medical decisions. That means asking the specialist the right questions...

- Are you sure of the diagnosis?
- How did I get this disease?
- · What factors make it worse or better?
- How long must I stay in the hospital?
- What should I expect as far as disabilities? Will the disease get worse?
- Can the symptoms be controlled?
- What treatments are available?
- Is the treatment you're recommending the latest?
- What is its success rate?
- What are the risks of this treatment?
- Do the benefits outweigh the risks?
- Are there any experimental treatments I should know about?
- If I take this medication for many years, what are the potential side effects?
- If I have surgery, will it stop the disease or will the process continue?
- What should I be doing to take care of myself?
- · What would make me feel better?
- What would make me feel worse?
- Is there anything I can do to slow the disease's progress?
- · Will I have to limit my home activities and life-style?
- What kind of emotional reactions can I expect?
- What can I expect for the future?

...You may also wish to bring your spouse, a close relative, or friend along to ask questions that might have eluded you. Take notes (or ask your friend to take notes) during this important visit. The doctor may impart too much information for you to absorb all at once in your state of anxiety, and you'll want an extra pair of ears to help you hear and record everything...

Finally, it's important for you *not* to feel stupid, intimidated or fearful. Your doctor needs you to comply with the treatments she recommends, and that's best accomplished if you understand what she wants you to do and why.

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## MEDIA

UNCOMMON FATHERS: REFLECTIONS ON RAISING A CHILD WITH A DISABILITY is a collection of essays written by fathers of children with disabilities. This diverse group of dads—including students, artists, teachers, a Christian missionary, a retired police officer, businessmen, attorneys and a rabbi—have children ranging in age from four to 28, with a variety of disabilities. Uncommon Fathers, edited by Donald J. Meyer and published by Woodbine House, is available through Exceptional Parent Library, (800) 535-1910. 206 pp; \$14.95 (paperback).

The following is an excerpt from "He Canters When He Can" by Greg Palmer:

When Ned was four he began exhibiting some classic autistic behavior, which I'm told is rare for a child with Down syndrome. He would go off into a corner for hours and babble incoherently to himself, while slowly, rhythmically rocking his body. We were concerned, of course, but not unduly. Otherwise Ned was a very happy, outgoing boy who was making good intellectual and physical progress. He especially liked phonograph records and television, and would listen to and watch the same material over and over again. His ability to entertain himself for hours, whether by record, videotape or his own internal, unintelligible monologues, was often a relief for us—a respite from the intense attention he otherwise needed.

A few years after the monologues began, he was rocking and talking one Sunday afternoon while I sat reading the paper, not paying any attention to the meaningless recitation going on nearby. And I suddenly heard him say, clearly, precisely and with feeling, "You're a very bad man. No, I'm a very good man, I'm just a very bad wizard." He was reciting *The Wizard of Oz...* 

I soon learned he had memorized all of *Snow White*, too, as well as *Puss In Boots*, most of the television episodes of Jim Henson's *Muppet Babies* and the songs on a dozen different recordings by Raffi, Fred Penner, Rosenschontz and others. It occurred to me that Ned had never been babbling incoherently, that all those years he was entertaining himself with the material he liked. I had underestimated him badly, and I've tried never to do that again...

I remember sitting on my front porch that September evening when we first learned that Ned had Down syndrome, and suddenly having the chilling realization that, not for as long as we lived but for as long as he lived, Ned would be our responsibility; not the state's, not his relatives', especially not his brother's. We could hope that some day Ned would be self-sufficient, and work as hard as possible with him towards that goal. We could trust that his older brother would take care of him in their adulthood, not because he had to, but because he wanted to. But we still had to be prepared for the physical, financial, emotional alternative—parental custody, even from beyond the grave. Loving Ned with all our hearts would never be enough.



That preparation, both of Ned and his world to be, has taken planning, patience and research, including knowing what opportunities are available within the community. Ned was three weeks old when he went to his first infant stimulation class... That was just the beginning of a quest for good schools, camps and experiences, a quest that will never end.

Even so, I've found the essence of raising a special child is not in the grand questions..., but the more immediate question of "What did you do with my watch?" While not losing sight of the big picture, it is the daily business of life, the million things we do at home with and for Ned, that seem to have the most beneficial effect on him, and us.

Just one example. I can't recall a time when Cathy or I haven't read to him in the evening right before he goes to bed... His current interest is biographies—Jefferson, Washington, Lincoln and especially Martin Luther King Jr. For 10 Halloweens in a row. Ned was the same witch, but this past year he finally wanted to be someone else. He wanted to be the Reverend Dr. King, as a tribute to a man he's read about and admires. It was a wonderful idea and we were proud of him, even if we didn't have the slightest idea how we were going to turn this little white kid into his hero without offending half the neighborhood, makeup-wise. (We decided on just a dark suit and glasses. To me, Ned looked more like Roy Orbison than Martin Luther King, but he was satisfied.) As his father, I know the memory of this past Halloween and the Martin Luther King Dilemma will eventually overwhelm any memories of a decade of trying to talk a very stubborn little boy out of that ratty witch costume.

I'm making Ned sound like the perfect kid, a constant delight to everyone all the time. That is not my intention, and not the case... Somebody must say it. Developmentally disabled children can be a real pain in the butt, and there is no guilt in a parent admitting that...

For all his occasional obstinacy, though, the hardest thing about being Ned's father is contemplating the future. I want no more and no less than for Ned to be happy every day of his life. But I judge happiness on my terms, from my experience. Happiness for me is being married for 26 years to a woman I love, and having children I love as well. Happiness is having good and talented friends, interesting work to do and the freedom to stop doing it for a while and just go somewhere. And Ned may never have any of these things...

The principal disadvantage of my decision always to deal with Ned's situation logically and realistically is that I can't shake it, even when I want to fantasize about a glorious future for him.

But that's a lot different than giving up. Only my own narrowness of vision makes me think that when Ned is 46, his idea of happiness will be what mine is now. And if there is some overlap, I know his mother and I have done all we can to get him ready...

He will be a very good man, and maybe a very good wizard.

# HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

### **Conversion Rights**

We live in Georgia. In 1987, our daughter was born with severe mental retardation. At the time, we had health insurance coverage as individuals in a group policy. Our policy was later transferred to another insurance company.

That insurance company terminated the policy in 1989. In order to continue health insurance for my daughter, who is considered "uninsurable," my husband and daughter continued health insurance on a conversion policy.

In the fall of 1994, our policy was again transferred to another insurance company. In April, we received a letter saying that this insurance company was terminating the policy. They say we can apply for coverage with another insurance company under our conversion rights.

How can they do this? What protection do we have against this happening over and over again?

A Since the federal government has not yet passed a health care reform act, the degree of consumer protection in regard to health insurance depends largely on state law. And that, of course, differs dramatically from state to state.

Some states, for example, have passed health insurance reform acts that guarantee important protections for consumers. In several of those states, the legislature has authorized the establishment of a series of standardized health insurance plans. Each plan has specific limits and exclusions; each plan provides a different level of benefits and a different deductible. Most importantly, however, these standardized health insurance plans are usually available to all applicants, regardless of their health status. This makes children and adults with disabilities eligible for health insurance coverage in these states.

In addition, these standardized plans are usually "community-rated." Community rating means that a company has to charge the same price to each applicant for the same health insurance benefits, regardless of the applicant's health status.

Georgia, however, has not yet passed a health care reform act, and does not currently offer either a community-rating system or a guarantee of eligibility for health insurance coverage. However, existing state insurance regulations may relate to your concerns.

The first step would be to discuss your situation and the existing regulations with the Georgia State Insurance Department's Consumer Services Section (716 West Tower, 3 MLK Jr Dr., Atlanta, GA 30334; 404/656-2070; 404/657-8542, fax).

You can ask specifically about state regulations in regard to termination of health insurance coverage by an insurance company, and about conversion rights. Conversion rights generally allow for a continuation of health insurance coverage under certain conditions, albeit under a new framework. If a group insurance plan that includes conversion rights is canceled, for example, it may be possible for consumers who were covered by that plan to continue benefits by converting to an individual policy.

State regulations may specify the conditions under which a health insurance company can terminate an insurance policy. In addition, there may be regulations requiring that coverage be continued under conversion rights when an insurance policy is terminated by a company, and that also require the new policy to include benefits similar to the original policy.

You may also want to review the health insurance plan offered by The Arc, The Arc Group Major Medical Insurance Plan. The plan is available to Arc members and their families. It was designed specifically to meet the needs of children and adults with mental retardation and other disabilities.

Although there's no guarantee of acceptance, the insurability of each applicant is individually evaluated. At

this point, children must be at least 10 years old to be covered by the Arc health insurance plan. However, since your daughter will be 10 in another year and a half, the Arc plan may provide an eventual solution.

At present, the plan is not available to residents of New Jersey, New Hampshire, Vermont or Connecticut, apparently because of conflicts with the insurance regulations of those states. However, it is currently available to residents of Georgia. For information about the Arc, call (800) 433–5255, voice, or (817) 277-0553, TTY. For detailed information about The Arc's insurance plan, contact the Arc's insurance administrator, The Albert H. Wohlers Company (1440 N. Northwest Highway, Park Ridge, IL 60068-1400; 800/323-2106).

I think it is also important to write to your legislative representatives—on both the state and federal level—about this issue. On the state level, you may wish to suggest that the legislature consider enacting a health insurance reform act that would provide important protections for children and adults with disabilities.

On the federal level, Congress is now beginning to debate health care and health insurance issues once again. I think it is essential that legislators at this level become more fully aware of the health insurance coverage difficulties now faced by families of children with disabilities.

In this column,
Richard Epstein
answers readers' questions about health
insurunce. Send your
questions to him at
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If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.



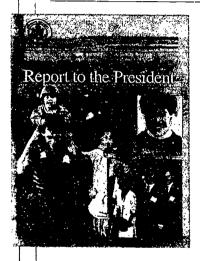
### WHAT'S HAPPENING

### No Place Like Home

An excerpt from the annual report of the President's Committee on Mental Retardation

The President's Committee on Mental Retardation (PCMR) has released its 1994 annual report entitled The NATIONAL REFORM AGENDA AND CITIZENS WITH MENTAL RETARDATION: A JOURNEY OF RENEWAL FOR ALL AMERICANS. The report, authored by Dr. Glenn Fujiura of the University of Illinois at Chicago, reflects the contributions of a number of self-advocates, parents, family members and professionals. It includes recommendations made within the context of welfare and health care reform.

Illustrating these recommendations are the stories of several individuals with mental retardation. The following is a excerpt from the section of the report entitled "Home."



...People with mental retardation can and do own and rent their own homes all through the U.S. Though little used to date, this is the most rapidly growing type of residential option. In localities across the nation, innovative funding options are being implemented.
State governments, including Colorado, Connecticut, Florida, Illinois, New Hampshire, Michigan, New York, Rhode Island and Vermont, have developed innovative financial assistance programs for cash assistance, leases, rent subsidies and vouchers.

David Guillet just purchased a condominium in Cumberland, Rhode Island. Formerly a resident of group homes, he, together with his parents, Marge and Lou, were pioneers in the development of home ownership options in their state. Through a collaborative effort of state agencies, they obtained a low-interest mortgage and a grant for the down payment, closing costs, and furniture.

Compared to publicly-funded group homes that often come with unneeded service packages and associated staffing expenses, home ownership may be less

"My son has very severe disabilities," said Mrs. Guillet, "quadriplegic, legally blind, with severe seizures. Yet, I have the same fears for David as I do for my other children, who do not have disabilities. We are helping David expand his relationships by introducing David to the fire department, to his immediate neighbors, by holding an open house. The neighbors were wary, assuming the state had purchased the condo. Their perceptions immediately changed when they found out that David was the owner, not some

"ward" of the state.

"We have choices now. We pick the support staff. David has complete control of the choices in his life. David can eat what he wants to eat, when he wants to eat. If he wants to wear a blue shirt with green shorts, that's OK. I can see the difference in his eyes."

The great challenge is to see beyond current service paradigms. Many people with mental retardation who receive residential services live in housing where services and personal assistance are based on group considerations and agency preferences rather than individual needs and choices. People with mental retardation are often wrongly viewed by government agencies and service providers as needing "special housing," rather than as individuals with idiosyncratic needs for support...

To obtain a free copy of The NATIONAL REFORM AGENDA AND CITIZENS WITH MENTAL RETARDATION: A JOURNEY OF RENEWAL FOR ALL AMERICANS, contact PCMR, 330 Independence Ave., SW, Wilbur-Cohen Building 5325, Washington, DC 20201; (202) 619-0634.

#### **Publications**

- Nutrition Care for Children with Prader-Willi Syndrome ages 3-9 is a 12-page booklet that addresses calorie needs, supplements, diet planning and food management, and explains food-exchange lists. Booklets are \$5 each and can be purchased from the Prader-Willi Syndrome Association, 2510 S. Brentwood Blvd., Ste. 220, St. Louis, MO 63144; (800) 926-4797.
- Medical Facts About Spina Bifida, produced by the Kennedy Krieger Institute in collaboration with the Spina Bifida Association of America, is a comprehensive information resource for parents of children with

spina bifida. Individual copies of the 12-page booklet cost \$4. Contact the Spina Bifida Center, Kennedy Krieger Institute, 707 N. Broadway, Baltimore, MD 21205; (800) 873-3377 or (410) 550-9000. • Living SMArt is a bimonthly newsletter written by adults with spinal muscular atrophy (SMA). The newsletter features information, networking and support for adults with SMA, as well as parents. Yearly subscriptions cost \$6; additional donations are welcome. For a complimentary issue, contact Living SMArt, c/o June Price, editor, 3576 S. 43 St., #32, Milwaukee, WI 53220-1550; (414) 541-2848; e-mail: LivingSMArt@aol.com.

• The 1995 Resource for People with Facial Difference is a comprehensive directory containing listings of organizations for people with facial difference, their families and

professionals. The directory also provides information on relevant publications, videotapes and audio cassettes. To receive a complimentary copy of this publication, send a self-addressed 9 x 12 envelope with \$3 postage to Let's Face It, Box 711, Concord, MA 01742-0711.





### **Education Department Submits Proposal** to Reauthorize IDEA

On June 30, 1995, the U.S. Department of Education submitted to Congress a proposal to revise and reauthorize the Individuals with Disabilities Education Act (IDEA). The proposal reflects comments from over 3,000 parents and educators. It marks the first substantial revision to the legislation since Congress enacted PL 94-142, the basis of the IDEA, in 1975.

The department based its proposal on six principles: (1) connect the IDEA with state and local education improvement efforts so students with disabilities can benefit from them; (2) improve educational results for students with disabilities through higher expectations and meaningful access to the general curriculum, to the maximum extent appropriate; (3) address individual needs in the least restrictive environment for the student; (4) provide families and teachers—those closest to students—with the knowledge and training to support students' learning; (5) focus on teaching and learning and (6) strengthen early intervention to help ensure that every child starts school ready to learn.

The proposed changes include:

- Increasing parental involvement by requiring schools to issue regular reports to parents on their children's progress, and by including parents in decisions about their children's placement.
- Providing parents and teachers with better training on helping students with disabilities achieve in school. A national network of parent training centers would be expanded. A professional development program would be expanded to help all teachers work more effectively with students with disabilities.
- Providing parents in every state the option of resolving disputes with schools over their children's education through mediation.
- Helping schools maintain safe and disciplined classrooms by allowing schools to move a student who has brought a firearm or other dangerous weapon to school to an alternative educational setting for up to 45 days.
- Improving school safety by permitting hearing officers to authorize the temporary removal to an alternative setting of a student who is substantially likely to injure himself or others.
- Promoting high expectations and achievement by focusing the individualized education program (IEP) on measurable annual objectives and achievement in the general curriculum, whenever possible, and by including the student's regular teacher in developing the IEP.
- Ensuring accountability for educational results by requiring greater participation of students with disabilities in state and district assessments, and by asking each state to establish goals for the performance of children with disabilities.
- Revising the formula for grants to states so that new dollars would be distributed based on the state's population, rather than on the number of children with disabilities being served. Current law tends to encourage over-identification of children—particularly minority children—as having disabilities. Current law also discourages states from doing early intervention and pre-referral activities.

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150	COLUMBIA MEDICAL	21
259	CONNETQUOT WEST	48
124	****	. 57
/4	CHYSTAL SPRINGS SCHOOL  CUMBERLAND HOSPITAL  DEVEREUX FOUNDATION	13
107	DEVEREUX FOUNDATION	24
105	DIFCE CO A SAMUE A CTUDING	48
	EPILEPSY FOUNDATION OF AMERICA	. 49
123	EQUIPMENT SHOP	12
31	ESTATE PLANNING ,	40
158	EXPRESS MEDICAL SUPPLY	62
135	FORD HARD MANUFACTURING	5
44	HARD MANUFACTURING HAVERICH ORTHO SPORT	. 43
166		
14	HDIS	31
3	HEARTSPRING	. 6
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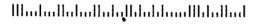
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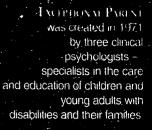
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### Information from The National Parent Network on Disabilities

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### Welcome to the World

The Americans with Disabilities Act (ADA), passed in 1990, has now existed for five years! This anniversary provides me with a chance to reflect on what the ADA will mean for children born with

Children born in the last ten years, thankfully, may not have experienced rejection and hostility because of their disabilities; I hope they haven't. Although our country was founded on the premise of hospitality-our forefathers sat together with the Native Americans to celebrate the first Thanksgiving—the United States also has a great deal of hostility threaded throughout its history. Often there has been no "welcome mat" for people of different nationalities or races, or even for people with different ideas. Similarly, discrimination towards people with disabilities has a disturbing past, one full of injustices. The ADA is and will be the "welcome mat" for children with disabilities today and in the future.

This is the message of the ADA to young children growing up with disabilities:

"You are welcome here—the corner curbs are cut for your chair... hearing devices are available at the concert... there is a space for your wheelchair at the movie theater... the grocery store has an extender to reach high shelves... McDonald's has picture menus... and the door handle and the light switch at Mom's office are set at a reachable level. You can go to school, participate in afterschool activities, enter the gymnasium and attend school dances.

"When you go to college, you'll find new freedom. You'll have an accessible campus, devices in each room to signal fire, accommodations to help with learning disabilities. But most of all, when you grow up and need a job, you'll find transportation to get you to work and accommodations to help you succeed in working. Local buses will pick you up. If you need to attend a business meeting in another city, you'll be able to fly there. You'll find accommodations to make working a probability and a reality. The ADA has opened these doors for you."

Do I have fears about ongoing hostility and further discrimination toward children with disabilities and their families? Yes. My fear is that young people and their parents may forget. If you don't remember the difficult past, you might become complacent and take things for granted. You might not realize how fragile our collective "freedom" is. You might forget the recent times when children with disabilities were denied entrance into schools and couldn't maneuver through society because they were not welcomed into it. In those times, they were viewed as a tragedy, sent away from home, set apart. They certainly were not accepted as important, contributing members of the community.

Changing the environment in this country from hostile to hospitable is the great gift of the Americans with Disabilities Act. Welcome to the world!

-Patricia McGill Smith

As EXCEPTIONAL PARENT was going to press, planning was underway for a celebration in Washington DC in honor of the fifth anniversary of the ADA. The event, "Voices of Freedom: America Speaks Out on ADA," was scheduled to take place on July 26, 1995.

### "Promises to Keep" Rally an Unparalleled Success

On June 22, the National Parent Network on Disabilities in cooperation with the Spina Bifida Association of America, the Bazelon Center on Mental Health, the Epilepsy Foundation of America, the National Association of Medical Equipment Suppliers, Justice for All and the Consortium for Citizens with Disabilities-staged a rally for the rights of people with disabilities on the west steps of the U.S. Capitol. More than 1,500 people from all over the country attended and made their voices heard.

The rally focused on the issues of preserving the Americans with Disabilities Act (ADA), maintaining the protections and funding of the Individuals with Disabilities Education Act (IDEA), maintaining funding for Medicaid and Medicare and protecting the children's Supplemental Secu-



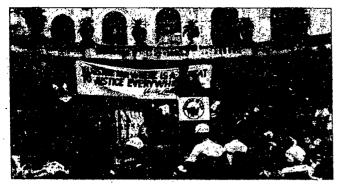
Senator Bill Frist, R-TN, asked for help in placing "the rights of people with disabilities above partisan politics." He was joined on stage by Patricia NicGill Smith, Becky Ogle, government affairs representative of the National Association of Medical Equipment Suppliers, and a young advocate of the future.



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continued on page 64

AUGUST 1995 / EXCEPTIONAL PARENT + 63



Senator John Chaffee, R-RI, emphasized the need to protect cash payments to children with disabilities who receive SSI—"Doesn't it make sense to keep people at home rather than in institutions?" On stage with Senator Chaffee was Patricia McGill Smith, NPND executive director.

continued from page 63

rity Income (SSI) Benefit Program.

Members of Congress expressed their support for the disabilities rights movement, and many of them voiced concern that the rights we have fought so hard to gain could be destroyed by the end of this session of Congress. Speakers included Senator John H. Chaffee, R-RI; Senator Bill Frist, R-TN; Senator Tom Harkin, D-IA; Senator Paul Wellstone, D-MN; Representative George Miller, D-CA; Representative William Goodling, R-PA; and Representative Sheila Jackson Lee, D-TX.

Paul Marchand, director of the Arc Government Affairs Office, opened the rally with a welcome from the Consortium for Citizens

with Disabilities and read a letter from Tony Coelho, chairman of the President's Committee on Employment of People with Disabilities, who could not attend. Gene Mitchener, an inspirational speaker from Los Angeles, urged the people in the crowd to speak for themselves. Justin Dart, a long-time advocate in the area of disability policy, closed the rally, speaking eloquently about the need to preserve the rights of people with disabilities.

Following the rally, participants called on their legislators. Parents, self-advocates and professionals hit the halls of Congress to spread the word. And although we were competing with the activities relating to the nomination of Dr. Vincent Foster for U.S. Surgeon General, it seemed clear on June 22, that Congress got the word! Now we must beat the drums and raise up a wall of parents the likes of which has never been seen. If not now, when? If not us. who?

#### Now available!

The "Promises to Keep" rally is available on videotape. This video is an excellent tool with which to open talks with parents and other advocates about the need to be involved in the legislative process. For a copy of the videotape, please send cash, check, money order and/or purchase order for \$33.95 (includes postage) to Inclusion Incorporated, 1436 Independence Ave. SE, Washington, DC 20003-1536; (202) 546-4464, (202) 546-4465 (fax), Internet: Inclusion@aol.com.

### **Women and Disability**

The International League of Societies for Persons with Mental Handicap (ILSMH) has recently initiated a four-year comprehensive program effort on behalf of women. The ILSMH has established an Action Group on Women and Disabilities, directed by Patricia McGill Smith, NPND executive director. The Action Group is developing positions and recommendations regarding women who have cognitive disabilities and their caregivers. In September, at the International Women's Conference in Beijing, Patricia McGill Smith will represent ILSMH by speaking on "Women Who Care, A Review of Gender, Disabilities and Family Life for Caregivers of People with Mental Disabilities." She has conducted a survey to gather the ideas, beliefs and experiences of women who care for those with disabilities, and welcomes any additional responses.

### Mark Your Calendars!

For more information, contact Gail Johnson, National Parent Network on Disabilities, 1727 King Street, Suite 305, Alexandria, VA 22914, (703) 684-6763

The NPND 1995 Annual Conference "We Have Promises To Keep"

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### **New PTIs**

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National Center for Latinos with Disabilities (IL Chapter) 1921 S Blue Island Ave Chicago, IL 60608 (312) 666-3393 (312) 666-1788 (TTY) (312) 666-1787 (fax)

AWARE (Assisting With Appropriate Rights And Education) 200 N Vineyard Blvd, Ste 310 Honolulu, HI 96817 (808) 536-2280

Northern Manhattan Parent Training and Information Center 120 W 105 St, #L1 New York, NY 10025 (212) 666-1300 (212) 749-5021 (fax)

Project Empower PO Box 851 Greenville, MS 38702 (601) 366-5707 MPACT (Missouri Parents Act) 3100 Main St, Ste 303 Kansas City, MO 64111 (816) 531-7070

COPE (Creating Opportunities for Parent Empowerment) 810 Potomac Ave SE, 1st Fl R Washington, DC 20003 (202) 543-6482

Pathfinder Family Center Arrowhead Shopping Center 16th & 2nd Ave SW Minot, ND 58701 (701) 852-9426 (701) 852-9436 (TTY)

Rhode Island Parent Information Network 500 Prospect Street Pawtucket, RI 02860 (401) 727-4144

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Circle # 195

### **DESTINATION: RAIN FOREST**

Destination: Rain Forest is an interactive CD-ROM that combines learning about the South American rain forest with activities encouraging vocabulary development, reading and writing. Users can create interactive electronic books; color or black-and-white printed art-

work; poetry; on-screen puppet plays and theater productions; journals, diaries and letters; research reports and multimedia presentations. Users select from a variety of backgrounds, on which they place "stickers" illustrating people, plants and animals. They can incorporate music, spoken dialogue and animation to create their own adventures. The program is available in both Windows and Macintosh versions and is TouchWindow-compatible.

Edmark Corporation, Redmond, WA 98073-3218

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Kids in Mind by Goshen Enterprises, Fair Lawn, NJ 07410

Circle # 197



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Baby's Book Nook is a clear acrylic three-part frame designed to hold drawings, photographs and illustrated children's books. It is intended to encourage curiosity, visual



stimulation and development of early physical skills—reaching toward the pictures, looking from side to side, lifting the head and bearing weight on the arms. This product is also suitable for use with older children with disabili-

ties. The Neo Nook is a smaller version that fits in a bassinet and is suitable for use with infants weighing up to 12 pounds. Both models include three black-and-white visual stimulation cards.

The Baby Look Company, Grand Rapids, MI 49503 Circle # 198

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TOP END by Action, Pinellas Park, FL 34665

Circle # 200

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For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).



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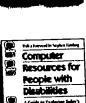


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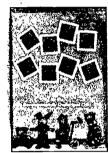
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### CHILDREN'S PAGE

### I'M PROUD OF MY SISTER

by Caitlin Crossman



Of five-year-old Blair, big sister Caitlin says, "I'm proud she is my little sister!"

writing.

y sister, Blair, is a twin. Her twin sister is Taylor. Blair has cerebral palsy. When she was a baby, she couldn't pronounce words. Last March, Blair had surgery, and I felt sad. Blair has braces and a wheelchair and a walker.

When we go out, people come up to me and ask me what is wrong with her. I say, "Blair has CP, but she is still a part of my family and I love her very much."

I am happy I am Blair's big sister, and I am proud she is my little sister! EP



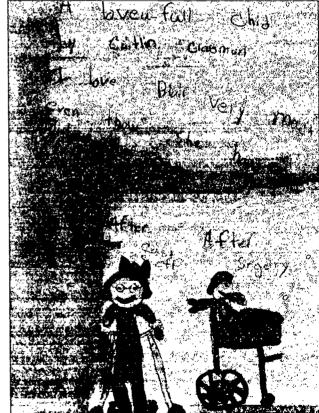
(From left) Taylor. Caitlin and Blair paused for a photo in front of the Christmas tree on their way to a holiday concert in December 1994.

Caitlin Crossman, 7, lives in Haymarket, Virginia. In September, Caitlin will be a second grader at Mountain View Elementary School. Her hobbies include gymnastics, horseback riding, drawing and

Twins Blair and Taylor, 6, will also be attending Mountain View Elementary in September; Blair will join an inclusive kindergarten class, and Taylor will be a first grader.

Wearing their shades, the Crossman girls, (from left) Caitlin, Taylor and Blair, enjoy a day at the beach during a 1993 family vacation at Nags Head, North Carolina.





the Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: Children's Page, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

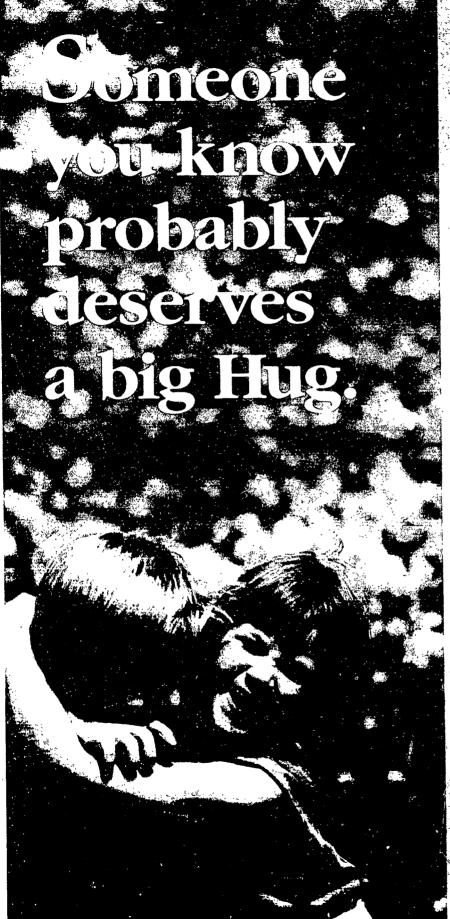
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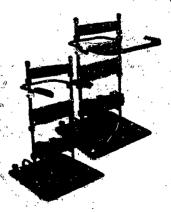
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SEPTEMBER 1995

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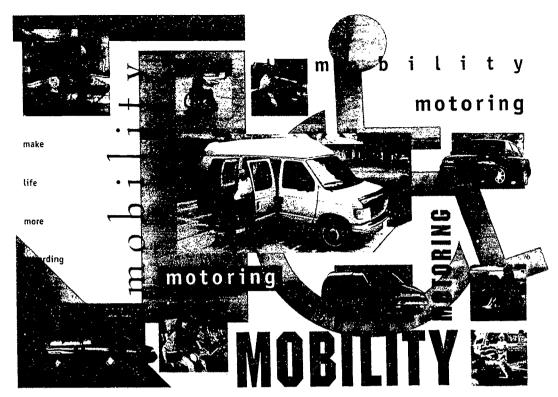
The Magazine for Families and Professionals

CHILD OR Young ADULT WITH A

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- a list of nearby assessment centers authorized lo provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- sources of funding which may be able to provide assistance in addition to the amount you receive from the Mobility Motoring Program

Best of all, you get Ford Motor Company's products and services. A Company where quality and service are always "Job 1!" So whether your life demands a new Ford or Lincoln-Mercury car or van, or Ford light truck ... just call 1-800-952-2248 (for TDD users: 1-800-TBD-0312). You'll discover that Mobility Motoring is your kind of reward!

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## EXCEPTIONAL

Contents

PARENTING YOUR

YOUR
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EDUCATION

ADULT
WITH A
DISABILITY

Quality: It's Everywhere by Gail Lieberman......34

Criteria by which educational programs can be judged.

Common Questions About Inclusion

The Magazine for Families and Professionals -----

Since1971



### **Departments**

Health Insurance Troubleshooter: THE USUAL AND CUSTOMARY RATE ................................89 Search & Respond ......11 New Products ......92 Fathers' Voices: BUILDING OUR FUTURE Exceptional Parent Library ......96 Role Models: Suzanne Miller ......30 Children's Page: THE SPECIAL VISIT 



PAGE 64



PAGE 75

COVER: Back-to-school time is time for new friends. Photo courtesy of The MED Group, 3223 South Loop, Ste. 600, Lubbock, TX 79423; (800) 477-6272; (806) 793-6480. fax.



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### EDITOR'S DESK

Choices, Quality, Respect

Educating children is a challenging responsibility for parents and professionals. In this our 23rd education issue, parents and professionals discuss this challenge—they share stories of successes, along with ongoing concerns. Many praise inclusive pro-



STANLEY D. KLEIN, PH.D.

grams; others argue convincingly against inclusion for some children with disabilities. It is clear that experience and research can provide guidelines, but they cannot provide any absolute solutions.

EXCEPTIONAL PARENT supports inclusion and alternatives to inclusion. Most of all, we support the expertise of parents as they endeavor to make wise choices for their children and families.

### IDEA: Your support needed

At the national level, we are fortunate that people like Assistant Secretary of Education Judy Heumann continue to advocate for children with disabilities and their families. In this issue, Judy

describes current efforts in Congress to reauthorize the Individuals with Disabilities Education Act (IDEA). The IDEA, a law signed just 20 years ago, has revolutionized our country's approach to the education of children with disabilities. We applaud Judy and her colleagues for proposing important "parent-friendly" modifications in the law—more parental participation, mediation of disputes and support for Parent Training and Information Centers. At a time when many political leaders argue for dramatic change, we urge our readers to speak up in support of the IDEA's reauthorization and these proposed modifications.

### 1995 Exceptional Parent Education Awards

In collaboration with the National Association of State Directors of Special Education (NASDSE), we have recognized programs that illustrate quality education for all children. These programs demonstrate  ${\bf v}$  hat can happen when dedicated professionals and parents work together to assure that every child is welcome and every child learns. Good education requires far more than philosophies and finances; most of all, it requires caring, thoughtful people who know that delivering quality education is always hard work.

Although most awards go to inclusive settings, we also honor programs that are not as inclusive as some would advocate. We believe that all children—with or without disabilities—deserve an education that respects their individual needs.

#### Respect for differences

Many recent issues have featured "Readers Talk About," a forum for parents to discuss perspectives on a variety of subjects. Sadly, differing opinions about education are not always respected. Some people believe every child should be educated in the regular classroom and criticize parents who decide their children are best served in other types of programs. Similarly, Exceptional Parent has been criticized for accepting advertisements from and writing about private educational and residential programs. This all-too-common climate of animosity makes this issue's "Readers Talk About" that much more impressive; in story after story, parents with strong individual opinions on educational placement go out of their way to express respect for those who have made different choices. These parents understand the message Exceptional Parent tries to express in every issue—that good choices for children are more important than loyalties to ideologies that too often ignore the fact that parents know their own children best.

#### To be continued...

Because we have an abundance of important material on education, we will present more articles on this topic in the October issue. We appreciate the assistance we received from NASDSE—an organization that deserves an award of its own—and the efforts of everyone who submitted award nominations.



YOUR CHRONE YOUNG ADORT WITH A DISCHAUTY

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For subscription and advertising information, see page 82.





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Before: Dec. 92

NOV. 93

### LETTERS

#### Thanks!

I've been reading your magazine for almost five years. I've loved every issue and read each one cover to cover.

Through your magazine I've found a diaper service for my six-year-old daughter and discovered equipment that she could use. But most of all, your magazine has helped me to accept the way our lives have turned out. Your articles always have something to do with what's happening in our lives. Thanks for a wonderful way to keep in touch with others who understand.

Lynın Schiermeyer Arlington, Texas

■ Seminars, parent group meetings, mail correspondence with others—I've been there, done that, tried it. My true strength has come from everyday life with my son and from EXCEPTIONAL PARENT.

I look forward to each issue with such enthusiasm. Although the stories in the magazine are about children with a wide variety of disabilities, they are all portrayed so honestly. The stories and pictures are from the very best source—parents. And even if some of the stories are sad, they make our family stronger and more appreciative of life with our son, Michael Junior.

Thank you for showing our children in their true light. They are all beautiful, and they all descrive to be seen and heard.

L.Z., New Jersey

#### Safety First!

I have been very surprised at some of the advertisements for bicycles in EXCEPTIONAL PARENT. Even my two-year-old son could see the problem with these ads. He 'looked at the pictures and said, "They're not very safe, Mommy." He was right! Both ads pictured children riding bikes without helmets.

I am quite sure your magazine does not want to promote the creation of more children with disabilities by encouraging head injuries. Exceptional Parent owes its readers sensitivity to safety issues and responsible advertising for products.

I called the toll-free number for one of these advertisers. When I complained that the children in their ads were not wearing helmets, I was told that was intentional—so the photos would "look good." Has this advertiser thought about how the potentially devastating results of an accident without a helmet would "look?"

Three cheers for parents and caregivers who teach their children that helmets mean safety. When neighbors ask my children why they wear helmets, my kids reply that it's "because Mommy loves me."

I hope Exceptional Pagent will ask future advertisers to put safety above "looking good." Please be a responsible magazine.

Marie Baca Bear, Delaware

EDITOR'S NOTE: We agree. We have asked our advertisers to revise these ads.

These Ads Don't Belong Here! I subscribed to EXCEPTIONAL PARENT magazine for up-to-date information and support as I raise three children

continued on page 6

### EXCEPTIONAL DARENT

To reach out to parents of children and young adults with disabilities and special

health care needs and to the professionals who serve families

To empower parents and professionals by providing practical information and emotional support.

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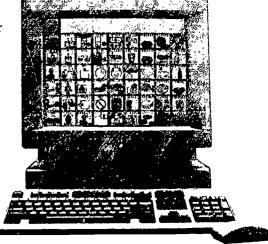
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continued from page 4

with developmental disabilities. You say the purpose of the magazine is "to reach out to parents..., to energize parents..." Many of your articles accomplish these goals and are uplifting as well. I thoroughly enjoy most of the features and read the magazine cover to cover.

However, I am deeply offended by some of the advertising. EXCEPTIONAL PARENT should not be a forum for those who advocate segregating members of our society at a "residential school in a beautiful country setting"—why don't they just say "institution?" Why should the parents of a beautiful child with Down syndrome be forced to read, month after month, that their child belongs at a school "where persons with Down syndrome find quality life experience?"

All people belong in the community with one another. Everyone's life experience is enhanced when we're together—not segregated. Flease take the position that these ads don't belong here.

J.V.S., Colorado

EDITOR'S NOTE: Since the first issue of the magazine in 1971, EXCEPTIONAL PARENT has consistently supported good educational and housing choices for children and adults with disabilities. In that context, we welcome advertising from accredited, private educational and residential programs. Periodically, we receive letters like yours, objecting to this policy. In the 1960s and 1970s, I visited inhu-

### Tell us about...

... your child's and family's experiences with early intervention.

Write to: Readers Talk, Exceptional Parent, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue. mane institutions; now, I visit many of our advertisers' programs. It is unfair to equate these private programs with institutions. I urge you to visit some of these programs and let me know what you think. In this issue, EDITOR'S DESK, RESPOND and READERS TALK ABOUT also discuss the need for parents and children to have choices.

"Bringing up Grandpa"

My husband and I are grandparents raising a six-year-old girl, who has been diagnosed with "features" of autism and cerebral palsy. We are so pleased to have the opportunity to subscribe to your m. gazine.

She is a bright, beautiful little girl who doesn't look like she has any disabilities. But spend five minutes with her, and you will realize she cannot carry on a "normal" conversation, nor does she walk. We have never seen another child like her. We have seen kids with cerebral palsy and kids with autism, but none like our grand-daughter. Even medical professionals don't have any answers.

In the meantime we take her everywhere we possibly can to get answers. People are always telling us, "She is so lucky to have you."

I always reply, "No! We are lucky to have her!"

I will close with one little story about our lives; I guess you could call it "Bringing Up Grandpa." Recently, I pulled a ligament in my knee, and doctors put me on bed rest. That meant Grandpa had to get Kelsi ready for school. The first morning, he brought her into the bedroom to say good-bye to me. He was so proud that he had gotten her ready for school. Her face was still sticky from the pancake syrup she'd had with her breakfast. She was wearing a pink turtleneck and a pair of red and white pajama bottoms! But her hair was combed, and the smiles on their faces were such a delight to see... but, I had to tell him that Kelsi couldn't go to school in her pajamas!

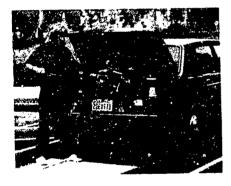
R.T. & S.T., Oregon

### PRODUCT NEWS



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Circle # 208

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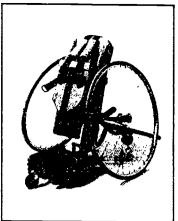
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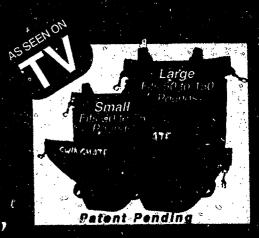
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M. Miller, Parent, tombard, It

66 Your ProtectaCaps are colorful and offer many good features for comfort. We will recommend them to our families. 99 Children's Hospital of Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia, Philadelphia,

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### SEARCH

### Undiagnosed

My daughter is now two years old. Her initial physical development was precocious. By nine months she was pulling to a stand and "walking" by holding onto furniture. At that point, however, her motor development seemed to stop. She walked unassisted at 21 months, but has poor fine motor control and slightly low muscle tone. She has no speech and few sounds, however, she seems to understand everything we say. She communicates through pointing, some signing and leading me to what she wants. She continues to have poor balance, and "fixes" her body at the joints for stability. She droots continuously and thrusts her tongue when drinking. She resists cuddling—unless she initiates it—and is very defensive about her face and mouth. She has extremely acute hearing, is easily distracted in group settings and is very active.

She has had the following tests: a brain MRI, hip X-ray, blood and urine tests for enzyme deficiencies and long-chain fatty acids, thyroid test, PKU screen, basic chromosomal testing and an audiogram. These tests revealed no abnormalities.

She has slight epicantal folds (vertical skin folds at the inner comer of her eyes); narrowing down the midline of her face, resulting in a high, narrow palate and nostrils; flat fingernails; fetal pads on her fingertips; a wide, flat ribcage and a few other mild physical anomalies. But geneticists cannot link these traits to any syndrome. Doctors have no more suggestions for diagnostic testing. I'd like to hear from anyone who knows of a similar child.

R.H., Connecticut

#### **Infantile Spasms**

My 14-month-old daughter is diagnosed with infantile spasms. Her disorder is the result of a stroke at 12 days of age. She has been slow in developing motor skills and has feeding problems.

I would like to talk to other parents of children with a single diagnosis of infantile spasms. I can't find much lit-

erature on the subject, so it is difficult to know what the future may hold.

N.M., Illinois

EDITOR'S NOTE: For more information on infantile spasms, see Dr. Hirsch's ASK THE DOCTOR column in the March 1995 issue of EXCEPTIONAL PARENT. You may also wish to contact the Epilepsy Foundation of America (4351 Garden City Dr., Landover, MD 20785-2267; 800/332-1000, voice; 800/332-2070, TTY), the American Epilepsy Society (638 Prospect Ave., Hartford, CT 06105-4298; 203/586-7505) or Epilepsy Canada (1470 Peel St., Ste. 745, Montreal, PQ H3A 1T1, 514/845-7855).

#### Seizure and Stroke

Our four-year-old daughter, Randee, was born with hydrocephalus and received a shunt at 11 weeks. She had slight developmental delays, but did really well until she was two and a half. At that point, she needed a shunt revision and developed tonic-cloric seizures. During a status seizure, she suffered a stroke. Randee was in a coma for eight days, and in the hospital for 68 days. When released, she was two years, 10 months old, and her developmental level was evaluated at four to six months.

Now, two years later, Randee walks with assistance, climbs on furniture, feeds herself finger foods and understands some things we say to her. One major problem is that she bites everything she gets her hands on—not just mouthing, biting!

I haven't found any other kids who have had a stroke as a result of a status seizure, nor can anyone give me advice about Randee's biting. I would love to hear from parents who have had similar experiences.

R.D., West Virginia

#### It Isn't Fair!

We are parents of two beautiful boys. Seven-year-old Brett has Down syndrome. His younger brother, Taylor, is two years old and has neuroblastoma (cancer of the neural cells). He has

continued on page 14

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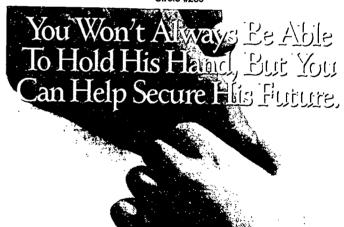
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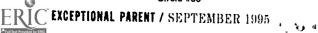
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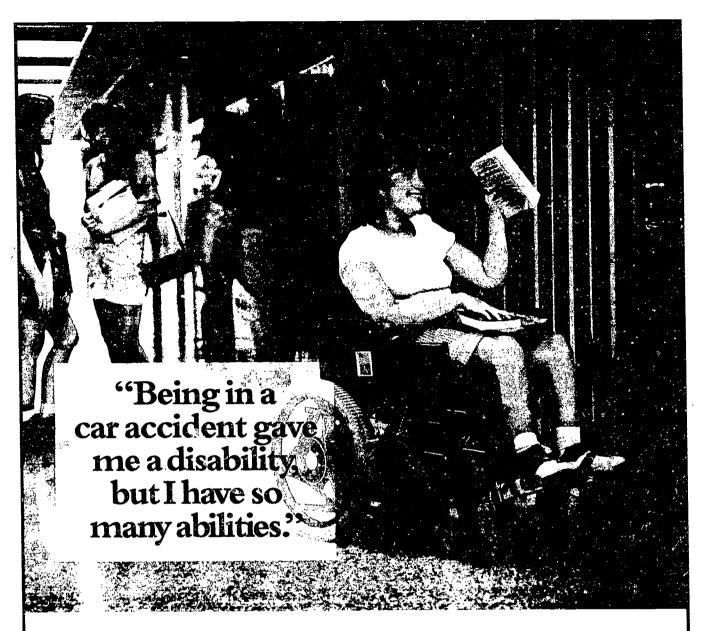
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### SEARCH

continued from page 11

been in remission for ten months. Now he is going through more chemotherapy in preparation for a bone marrow transplant.

This just seems so unfair to us. Everyday, we ask how God could do this to us twice. It just seems so overwhelming to deal with two children, who both have problems. We would love to hear from other families who have dealt with similar situations.

K.S. & K.S., New York

### Cerebellar Atrophy

Our 28-month-old daughter's recent MRI (magnetic resonance imaging) showed significant cerebellar atrophy since her previous MRI at seven months. The doctors just say, "This is interesting." Our daughter is undiagnosed. She has developmental delays in all areas with low muscle tone and a seizure disorder. We want to talk to families dealing with a similar condition.

L.B. & M.B., Minnesota

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and

> Write or fax: Search or Respond. Exceptional Parent 209 Harvard Street, Suite 303, Brookline, MA 02146-5005 Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in Exceptional PARENT'S 1995 Resource Guide (January 1995).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Farents are matched with a "veteran parent." who has an older child with a similar condition and who is willing to provide guidance and support. Concact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (V/TTY).

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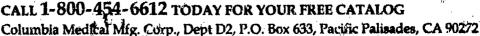
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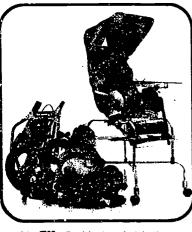




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### RESPOND

### **Residential Care**

K.S. (July 1995) has a three-year-old son diagnosed with infantile spasms, microcephally, mental retardation and autism—conditions causing severe behavioral problems. Exhausted, and feeling unable to provide the extensive care her son needed, K.S. placed her son in a residential care facility. Heartbroken, she wanted to hear from other parents who have gone through the same experience.

At a time when so many children with severe disabilities are cared for at home, it's hard to find understanding for families where this just isn't possible. Although our situation is different in detail than yours, I thought I would share our experiences.

Our daughter, Emily, has profound mental retardation, cerebral palsy, scoliosis, a seizure disorder and other disabilities. I was constantly tired from all the trips to doctors and therapists—along with six tube feedings a day—but when Emily was young. I coped. But as she got older and heavier, it became more difficult. Try lifting a six-year-old with the muscle tone of an infant. At best, it was difficult; other times, it was impossible. Sometimes, Emily missed school because I couldn't get her dressed. Other days, she stayed home because the one-hour bus ride was too strenuous for a medically-fragile child. She missed more than a quarter of the last school year she lived at home.

Meanwhile, we'd had two more children. At the time, we thought Emily might eventually learn to sit unsupported and feed herself, and figured we should get the pregnancies over with before she became much heavier. Life wasn't easy for my young sons either; while other kids went to museums and parks, we went to doctors and therapists.

We begat the placement process when Emily was six and moved her when she was seven and a half. Our sons were four and two. As a lifelong Episcopalian, I found the church, as well as society, sadly lacking any ritual to help families with this type of transition. One Sunday, we requested prayers "for Emily, who is entering a new school." Our church prays for people who are getting married, joining the Army or going through other life changes, but our prayer request was a new one. As it turns out, now that I'm no longer perpetually exhausted, I can bring Emily to church almost every time she comes home-every other weekend-which is more than I did when she lived at home.

To help our sons, we made sure they got a good look at Emily's school. The first evening after her move, our two-yearold son worried his sister wouldn't get any dinner because he didn't think the school had a kitchen; we made sure he saw the kitchen on his next visit! Our older son wanted to write a letter to the school staff, so we helped him with that. We also used little "tricks" to help the boys look forward to her visitssuch as saving special toys for her weekends home.

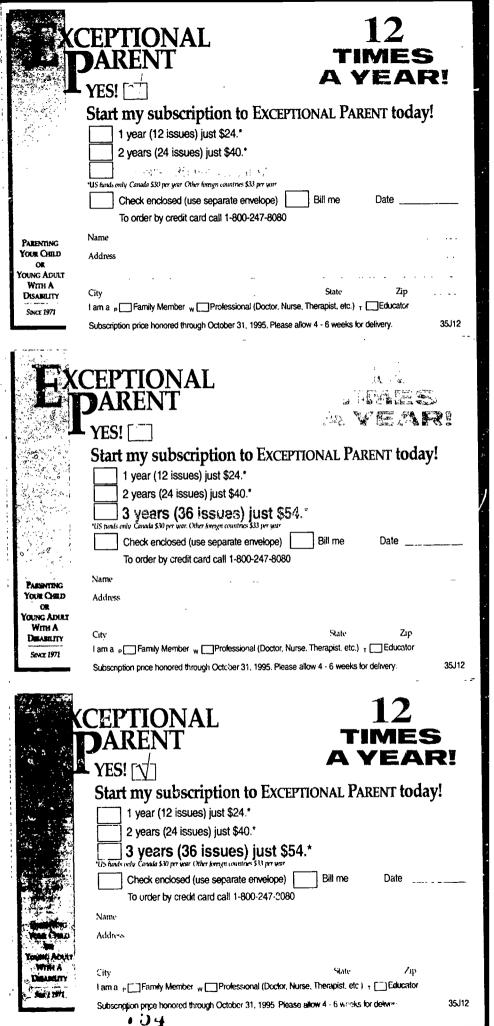
Relationships with school staff are important. When Emily had surgery after about eight months at this school, staff members visited regularly. I watched Emily's face light up when they came into the room. It's important to realize that staff members have bonded with Emily and consider her to be "theirs" in some ways. For example, with our consent, they let

continued on page 20

### School Period CTO areat exhibitation of its kind ... it le enuel reeding for all those with a hendicepped chilid. It could change meir kues." Ann Landers. ion of Ann Landens Thighly recommend Exceptional Parent magazine to all parents of children with disabilities." T. Berry Brazelton, M.D. Speaking as both a magazine publishing ensculive and as a father of a disabled child. I TOTAL PROPERTY. with safety of second of MANUFACTURE STREET acid his tracinational and e reducedly applicati content ... I would not miss an lesses ... from a man who reads perhaps TO magezines a recent, that's service a lot." James A. Autry

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continued from page 16

her hair grow long and "do it up" in fancier braids than I would ever try. They also choose some of her clothes. This does not mean we give up control on important issues, but we know we need to allow the staff to enjoy Emily.

Obviously, no school is perfect. But Emily's life at home was also far from perfect. Neither do Emily's brothers enjoy the luxury of perfection—at home or at school. Life isn't perfect anywhere; we just do the best we can.

Our close friends—the ones who watched me struggle to care for Emily-understand why we made this decision. Other, well-meaning friends hint that Emily would be better off at home, or that we just didn't try hard enough. I've memorized a few pat answers: "Emily is so lucky that special education is year-round at her school" or "She's so much better rested now that she's not riding a school bus two hours a day." Then I just change the subject. Any concerns you feel about your son's residence—and there always will be some—are best shared with just a few very close relatives or friends.

M.D., Maryland

■ I know how you're feeling. My daughter, Becky, now 15. was born with an occipital encephalocele (an opening in the base of the skull through which the brain protruded). This resulted in blindness, cerebral palsy and severe mental retardation. Becky requires total care.

We placed Eecky on June 27, 1994. Last summer, I don't think a day went b; that I didn't cry. Even now, I'm dealing with the guilt I feel, and I miss her so much.

On the other hand, Becky has grown so much in the past year. We visited her last week and were so pleased to watch her bring a spoon to her mouth to feed herself—a new skill! It helps to see Becky learning new things and growing in ways she could not have done at home. Best of all, Becky now has a friend! Like Becky, Jenny has severe mental retardation, but I feel so good to see the two of them relating to each other as any two buddies.

The hardest part was giving Becky's care over to other people. I'd done everything for her, for more than 13 years—feeding, changing, bathing and dressing. These rituals were a big part of our relationship. As my two other children grew up, I watched them gradually do more and more things on their own. But with Becky, one day, I was caring for her totally; the next day, I was doing nothing for her. What a shock!

The people at Becky's school have been wonderful, and have helped me understand that an adjustment like this takes time, and that all my feelings are normal. I hope my story helps you, and I hope you hear from other parents. too. I'm still adjusting myself; after one year, the pain is still there, but it has lessened.

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If you need financial assistance, Chrysler offers cash rebates towards the purchase of adaptive equipment through the Chrysler Corporation Automobility Program. Ask your local Braum distributor about other sources of assistance.

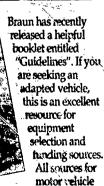
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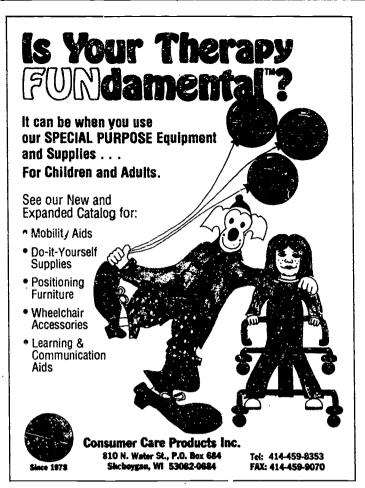
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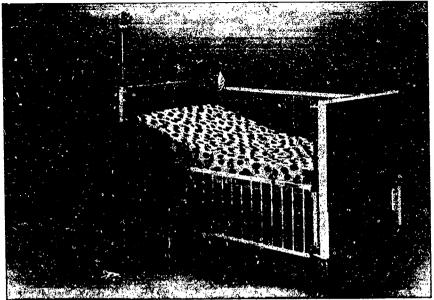
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# **Faces of the Special Olympics World Summer Games**

Although the competitors at this year's Special Olympic World Games in New Haven, Connecticut represented over 140 countries, they were united by their commitment to athletic excellence, sportsmanship and, of course, fun!

EXCEPTIONAL PARENT is honored to recognize the outstanding efforts of the participants and their supporters. Here are some of the faces of the 1995 Special Olympics World Summer Games:

Daxton Miller, 16, of Wichita, Kansas (left) and doubles partner Darren Hodgson (right) get a pat on the back from tennis star Pam Shriver (center) at a ceremony honoring their achievements. Daxton, who has mild mental retardation and was com-



peting for the first time in the World Games. won a gold medal in the sinales competition and a bronze in the doubles competition. "He felt really good about being

involved," says Daxton's father, Harold. "He thought it was nice to meet people from different countries. He enjoyed the competitive nature of the games." Recognizing Daxton's achievements, Wichita mayor Bob Knight proclaimed July 18, 1995 "Daxton Miller Day."

**Swimmer Rusty** Corley, 17, of Jamestown, North Carolina (seated) steps onto land for a moment to smile for the camera with his twin brother, Robbie (standing). Rusty, who has cerebral palsy and hydro-



cephalus, won a gold medal in the 25-meter freestyle and a bronze in both the 50-meter freestyle and the 25-meter relay. "He went to win, but he also went to have fun. He did both," said his mother, Bea. Though this was Rusty's first time competing in the World Games, he has competed in the North Carolina State Special Olympics for the past five years. Rusty wasn't sure at first that he'd like competing again but decided that winning "felt pretty good."



Twelve-year-old Nicole Lowrie of Largo, Florida warms up for her balance beam routine. Nicole has an . atrial septal defect---a hole in her heart, attention deficit disorder, a cleft palate and mild mental retardation. She received three

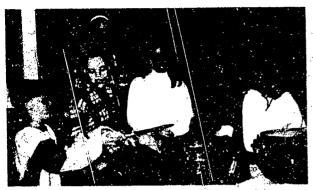
medals in the gymnastics competition including a gold in floor exercise, a silver in vaulting and a gold for her overall score. Nicole's developmental psychologist originally suggested gymnastics as a sport that could boost Nicole's self-esteem-advice that appears to have been accurate! "I had lots of fun, made new friends, and all the hard work was worth it," says Nicole.

Jon Derr, 16, of Swampscott, Massachusetts, gives us another reason to salute-his bronze medal in the golf competition. Jon, who has Down syndrome, had the support of more than 200 counselors and fellow campers from Camp Ramah of New England in Palmer. Massachusetts.

who came in three school buses and two vans to watch their friend take the green. Although he didn't win the gold, Jon realizes it's his commitment that matters. "I did my best," he says. "That's what counts."



# Familiar Faces



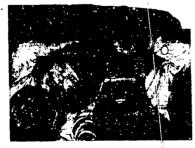
Blake Austin, 11, (second from left) of Littleton, Colorado, is a very enthusiastic percussionist in his school's sixth-grade band. Blake, who has multiple disabilities including cerebral palsy, mental retardation, visual impairment and a seizure disorder, seems to have a knack for beating obstacles as well as the drums. "Blake is the first student with severe disabilities to be in band at his school," writes mom Stephany. "It's his favorite class."



Brock Davis, 6, (left) and best buddy Kaegan Witherow put on a puppet show for other members of their kindergarten class in Muscatine, Iowa. Brock, who has cerebral palsy, is a "pretty popular guy" with his classmates says mom Barbara. She adds, "We

firmly believe that Brock's inclusion has enhanced his motivation to learn and be independent—just like all his friends."

Lean on me! Emily
Jean Mailman, 4,
(right) of Windsor
Locks, Connecticut,
gladly shares a shoulder with her best
friend Allison Pepin, 2.
Emily has Down syndrome "put in our
neighborhood," w:ite



parents Linda and Matt, "she is just one of the gang and participates in all outdoor activities with her buddles."

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readars' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was an, address and daytime phone number, and identify everyone in the toto. If you like, you can also write a few sentences about your child. In look for a familiar face in an upcoming issue!

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The certification program also includes customer service and safety training. From day one, technicians are taught the importance of excellent customer service, safety and comfort. The MED group believes that being technically competent is only part of being a complete technician.

MED-certified repair centers set unprecedented standards in the medical equipment industry for professionalism, technical competence and customer service. All work is guaranteed.

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# fathers'



On a family vacation, Nicholas and Dad get ready to take the boat out for a spin on Pelican Lake,

emember when you were young and built a snowman or a sand castle? You were so proud. Then, the next day, you went out to the back yard or down to the beach and found total devastation.

That's how I felt the day my son was born. When the day started, I was filled with excitement and anticipation; just hours later, I was running down the hospital hallway beside my sister-inlaw and a nurse, who was pushing my wife's stretcher into the emergency room. Days seemed to pass before the doctor came out and said my wife was fine, but the baby might not make it.

My new son, Nicholas, was going to be sent to Children's Hospital, and I went along. The ambulance ride seemed to last forever! I kept wondering if my son would live and how my wife must be feeling, all alone at the other hospital. What a mess! How could something so beautiful turn so ugly?

The doctor at Children's Hospital said that Nicholas had suffered oxvgen deprivation and was having seizures. Nicholas was on a lot of medication and the doctor told me, "The prognosis isn't good, but time will tell. Kids are tough.'

column are encouraged.

# **Building our Future**

by Mark Brown

I didn't want to leave for fear Nicholas would die without family by his side. So I waited. And every day, as I waited, the medications started to wear off. Finally, Nick started to wiggle.

During those long days by his bedside, my son became a passion. "Think positive!" I

kept telling myself. I sang to Nick, read to him, talked to him; I still don't know if I did all those things because I was tired or because I was going crazy. Then one day, exhausted, I fell asleep next to Nick's bed. When I woke up and looked at him, he was looking back at me! At that moment, I knew he was going to live. I was so happy. I felt a burning deep inside my heart.

changed the day Nick was born. Nick ended up with a diagnosis of cerebral palsy. Our life consists of braces, doctors, testing, neurologists, eye patches, physical therapists, occupational therapists, adaptive equipment, tight schedules and a whole lot more. But our family and friends have come together to give us love and support.

Though Nick is only two years old, he has accomplished so much. Yes, Nick has disabilities—he can't walk, talk or sit very well. But he can smile, laugh and cuddle. He can nod "yes," shake his head "no" and make the sign for "music." He hugs and gives kisses. Nick is beautiful, he's ours and he's here!

Our whole family keeps building those snowmen and sand castlesno matter what the next day brings. Every day, we hope to build one better and stronger than the one we built the day before. **EP** 

On his second birthday, Nick found a way to have his cake and eat it too.



Finally, Nick's mom got to visit for the first time. That visit made me realize why God made moms and the important role they play in a child's life. Nick started eating a little. After nine days in the hospital, Nick was ready to come home. For our family, everything

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their chil-'s and families' lives.

Mark Brown lives in Shakopee, Minnesota with his wife, Audrey, and their children, Ryan, 9, Kelly, 6. and Nicholas, 2. Mark is a manager at Anchor Glass Container Corporation. In his spare time, he enjoys hunting and fishing.









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# Role moders

# **Suzanne Miller**

"You can do everything with one hand"

Suzanne Miller, 54, has taught elementary school for 28 years—the last 25 as a special education reading teacher in the Waukeyan, Illinois public schools. She works primarily with students who have learning disabilities. Miller suffered a stroke at 14 months, which weakened her vision and the left side of her body. The following was adapted from an interview between Miller and EXCEPTIONAL PARENT intern Michele San Filippo.

was perfectly healthy when I was born. Then one night, when I was 14 months old, I got very sick. My parents put me to bed, but I didn't wake up the next morning. They rushed me to the hospital, where doctors said I had polio. Four years later, however, a doctor from Temple University looked at me and said, "This young lady never had polio—she had a stroke or a cerebral hemorrhage."

As a young child, I attended a "regular" nursery school, then went to parochial school. I had a difficult time adjusting to wearing my leg brace. The other children used to make fun of me. In the fifth grade I also got glasses; not only did I limp, now, I was a "four-eyes," too.

My father worked as a sales manager for Oscar Meyer and Hi-Grade Food Corporation, so we moved around a lot. My sister, Jane, hated moving and used to get mad because I would be so excited to hear about our next move. I would clap my hands and say, "Yippee!" I must have thought that by moving to a different state, I could forget my bad experiences in school and start over.

### Tough love

It didn't matter what happened at school—at home, my parents emphasized that I was no different from anybody else.

I remember one day I dropped a piece of paper on the floor. I expected my parents to pick it up. They refused. I said to my father, "Well, if you're gonna do this to me, then I'll just run away."

He opened the door and

He opened the door and said, "Good. Leave."

And there I was—out on the porch. It was wintertime. It was snowing,

Suzanne, 6, enjoyed riding her tricycle around the neighborhood.



The Miller family (from left)—Jane, Margaret, Suzanne and Frank—celebrated Suzanne's 1960 graduation from Framingham High School in Framingham, Massachusetts.

and my father wouldn't give me a coat! I kept banging on the door.

"Are you coming in?" he asked.

"Yes."

"Fine," he told me. "Now go pick up that piece of paper." "No!"

We went through this routine four times. I was getting colder and colder. Finally, I came in and picked up the paper. What can I say? I'm stubborn!

My parents stressed independence for my sister, too. They wanted her to have her own life. When I would drop things, Jane would run to pick them up, but my parents would tell her, "No. Don't do that. You have to let Sue take care of herself."

### High school

My high school years were difficult. During my freshman year at Springfield High School in Springfield, Pennsylvania, I had to have a let of orthopedic surgery. And by my junior year, my family had move—gain—this time to Framingham, Massachusetts. In many ways, I was a typical teenager, I wanted to be included in all the activities, but wasn't always accepted.

Even in high school, I knew I wanted to be a teacher. But because of my hang-up about my disability, I came up with the idea that I would become a teacher for children who were blind—because they wouldn't be able to see my disability.

### "I referred myself?"

After graduating from Butler University with a degree in elementary education, I started applying for teaching positions in public schools. I'd make it through the screening process and get an interview. But "mysteriously," I was never offered a job. I finally found a two-year position teaching fourth grade at a parochial school. But when they didn't ask me to continue, I was back where I started.

At this point, I remembered what one high school counselor had told me—"If you ever run into any problems with



EXCEPTIONAL PARENT / SEPTEMBER 1995

employment, remember the federal government has an obligation to see that you are employed." So I looked up the state vocational rehabilitation commission and made an appointment.

As soon as I walked into the office, they asked, "Who referred you to us?"

I said, "I did."

Then they asked again, "No. Who sent you to us?"

I said, "You don't understand. I did... I feel I am being discriminated against, so here I am."

Vocational rehabilitation enabled me to go to Northern Illinois University and get my master's degree in reading. They told me to pay for the first semester, and if I got through it with good grades, they would pick up the tab for the rest.

### Getting into special education

I never intended to go into special education; I just knew I wanted to help kids learn to read. I enrolled in an introductory special education course only because at that time, you needed at least one special education course to get teaching certification in Illinois.

When I was close to graduating, I went for an interview with the Waukegan public schools. And the interview turned out to be with the director of special education. The

position would involve teaching reading to children who were in special education. I got the job, and I've been teaching in the Waukegan public schools ever since.

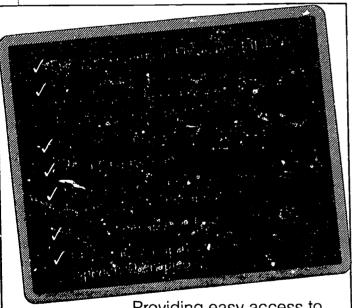
During the last 25 years, I've seen special education come a long way. The children are a constant challenge for me. You can't baby these children; you have to respect them. You have to set limits and provide structure. As educators, we have to get our students ready for the working world, and enable them to help themselves.

Sometimes, I feel my disability gives me an advantage over other teachers. I can ask a child, "Would you like to help me do this? You know I really can't do it very well." By letting them see my strengths and weaknesses, they learn to see their own. They always say things like, "Well, I can't read" or "This is hard for me." And I say, "Well, I can't run and jump."

Sooner or later, the kids always want to know what's wrong with me. When they ask, Suzanne and younger sister, Jane, helped their father celebrate his 80th birthday at his home in Florida.



continued on page 32



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Circle #77

# Role Models

continued from page 31

I just tell them, "I was sick as a baby," and let the subject drop. Then I wait. About three or four weeks later, they start raising their hands and asking questions: "How do you wash your hair?" "How do you take a bath?" "Does somebody live with you to take care of you?"

One day, one little boy got tired of all the questions and said, "Look, just leave Miss Miller alone. She told you she was sick when she was a baby. And

besides, you can do everything with one hand. The second hand just helps the first hand do things faster."

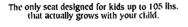
My most rewarding moments as a teacher are when children I had in the past come back to me and say, "Hey, Miss Miller, remember me? I'm in college now! I have a job and this is what I'm doing..." It's very rewarding to see their accomplishments and to know that I have made a difference in their lives. **EP** 

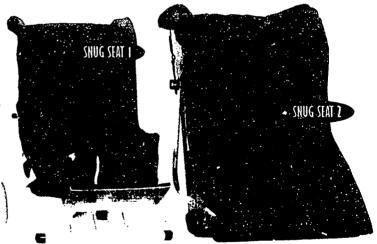


"Miss Miller," as she is known to her students, always encourages her classes to use their imaginations—especially on Halloween! Serving as an example of creativity, she dressed as a scary skeleton (far right) for this class picture.









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# Quality: It's Everywhere!

by Gail Lieberman



hen I read magazine articles listing good restaurants or recreational areas, I often wonder, "Why isn't there an exam-

ple from my community? Don't we have one, or is it that people don't know about what we have to offer?" It's the same way when it comes to schools. One school may become a "lighthouse" and attract people from many miles around. Another equally-good educational program may remain the best-kept secret in the state!

For this article, my colleagues on the board of the National Association of State Directors of Special Education helped me identify some hallmarks of quality educational programs. As one board member, John Corpolongo of Oklahoma, told me, "Quality in special education is like quality in any other endeavor. It starts with the assumption that what is being delivered can, and must, be improved upon. With this assumption, special education continually evolves in a dynamic process as families and professionals gain new knowledge and insights."

Interspersed throughout the following 14 pages are profiles of the schools and programs that are recipients of the 1995 EXCEPTIONAL PARENT Education Awards. Even if one of these programs is not in your community, please consider some of the criteria by which program quality can be judged. You may find these signs of quality in your local educational programs:

- A unified educational program in which administrators, teachers and parents support the education of all children in a system that values unity rather than segregation.
- Collaboration among all staff members.
- Ongoing professional development

that includes and focuses on families.

- A focus on problem prevention.
- Extensive use of assistive technology.
- Major *curriculum adaptations* to accommodate student needs.
- Student involvement in local and state assessments.
- Active inclusion involving interaction with other students rather than passivity and isolation with aides or other adults.
- Transition support for the family and student as he or she moves from secondary to post-secondary services.
- Partnership and commitment in all activities related to students with disabilities.

Getting what we expect

What do you need to ask of schools and school systems in terms of quality? Consider yourself a shopper seeking to fill an identified need—your family is the "buyer;" the school system is the "seller." In the *California School Board Journal*, Judy Smith-Davis wrote about assessing promising practices in an article entitled "We Will Get What we Expect." Her questions can help you find quality in your community:

- Claims: Ask yourself, "What goals and objectives am I looking to fulfill?" Ask the school, "What goals and objectives are your practices designed to achieve?"
- Effectiveness: Ask yourself, "How stringently should effectiveness be demonstrated?" Ask the school, "What evidence proves this practice is successful in achieving what it claims?"
- History: Ask yourself, "What are the qualities that define my local setting?" Ask the school, "In what administrative, geographical and educational settings has the practice been used?"

1995

**EDUCATION** 

# Marseilles Elementary School, Marseilles, Illinois

Over the past few years, Marseilles Elementary School
District #150 (MES) has worked hard to develop the best possible education program for all children—both "regular" and
"special needs" students. Recause my gight year old daughter

"special needs" students. Because my eight-year old daughter, Mary, who has cerebral palsy, stays in her own town to go to school, she has made many friends she might not have made otherwise. As a result, she is involved in many community activities including church and library activities, horseback riding and swimming lessons.

In the past few years, MES has:

Brought special needs students back to their

- home school.
- Created a full-inclusion program using all adaptations necessary to meet students' needs.
- Remodeled the school building in compliance with federal and state ADA and IDEA regulations, and even gone beyond requirements by building a three-story elevator.
- Organized an inclusion committee involving teachers, administrators, parents, school board members and community members.

Provided training for teachers.

MES does its best to help each student meet his or her highest potential. Mary absolutely loves school and for that we are very thankful.

Nominated by Julie Hettel, parent



Mary Hettel, a student at Marseilles Elementary School, gets a hand (or two) from Mrs. Saunders, her personal assistant.

- Implementation: Ask yourself, "What kinds of training or assistance are needed to implement a new practice?" Ask the school, "How is this practice taught to families of new students or new faculty members? What follow-up and problemsolving assistance is given?"
- · Change: Ask yourself, "What is my timeline for producing change? What is my criteria for judging success?" Ask the school, "How rapidly does this practice achieve its goals? Do you have evaluation procedures for measuring success?".

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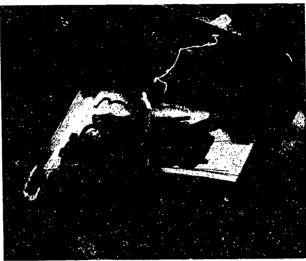
Finding quality in your community Some signs of quality in your community may be obvious. You may need to discover others, so they do not remain a secret. Still others you may need to create-in partnership with other local families and professionals-for your child and for future schoolchildren.

As my colleague Bill East from Alabama says, "Quality special education is realized when all Alabamians live, learn, work and play in communities where the worth of every person is valued, where individual needs are supported and where opportunities are barrier-free." This statement defines quality education for every community. EP

Gail Lieberman is the president of the National Association of State Directors of Special Education (NASDSE). She has been a special educator and has worked for the state of Illinois, in various capacities, for 24 years. Gail is married, and has a nine-year-old daughter. For more information about NASDSE, contact Dr. Martha Fields, Executive Director, NAS-DSE, 1800 Diagonal Rd., Stc. 320, Al wandria, VA 22314, (703) 519-3800, voice; (703) 519-7008, TTY.

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# **Common Questions About** Inclusion

What does the research say?

by Dorothy Kerzner Lipsky and Alan Gartner

What is the definition of inclusion? There is no official definition of "inclusion." However, based upon extensive study of inclusive programs and consultation with educational leaders, the National Center on Educational Restructuring and Inclusion (NCERI) has developed the following working definition: "Providing to all students, including those with significant disabilities, equitable opportunities to receive effective educational services, with needed supplementary aids and support services, in ageappropriate classes in their neighborhood schools, in order to prepare students for productive lives as full menibers of society."

Are there any full-scale research studies of inclusion? Inclusive education programs are a relatively new phenomenon. As a result, there have been few full-scale evaluations of outcomes. Researchers

have studied individual programs, and several statewide and local evaluations are currently underway.

A statistical technique, known as meta-analysis, allowed researchers Baker, Wang and Walberg to combine results from many studies and compare the effects of inclusive versus noninclusive settings. Their study found "a small-to-moderate beneficial effect" of inclusion on academic and social outcomes, meaning that "special-needs students educated in regular classes do better academically and socially than comparable students in noninclusive settings."

Summarizing several studies in a report to the President's Committee on Mental Retardation, Nisbet concluded that inclusion resulted in positive experiences and improved attitudes for children with and without disabilities, and also for their teachers. She added, "There is also some convincing evidence that integration or part-time mainstreaming does not

accomplish the social benefits of inclusion."

In its summary of 10 regional hearings, the National Council on Disability reported that a majority of witnesses testifying on the subject of "least restrictive environment" indicated strong support for inclusive placements. Many parents stated that their children with disabilities made greater academic and social gains in integrated settings. Parents reported that their children were happier in inclusive classrooms and were eager to be doing the same activities as their peers. This testimony reinforces the results of several other research studies and parental reports included in the national studies of inclusive education conducted by NCERI.

Are students with mild and moderate disabilities successful in inclusion programs? Overall, studies comparing differences between inclusive and segregat-

# Tobey Elementary School, Vicksburg, Michigan

Tobey Elementary School provides a comprehensive program for students with developmental disabilities. Through careful planning involving parents, the staff works to meet the academic, social and recreational needs of these students.

For example, Joseph Manslei, an 11-year-old with cerebral palsy, has attended Tobey, his home school, for the last two years. Joseph requires assistance for feeding, toileting, wheel-

chair mobility and classroom computer work. The staff has been creative in

**Tobey Elementary** School student Joseph Manslei (center) joins a teacher and a classmate to explore the world of science.

finding solutions to meet these needs. His classroom has been adapted so he can 1995 be either in his wheelchair or a prone EDUCATION stander. He has a full-time health care aide, as well as physical, occupational and speech therapists. He now has a fiveminute bus ride to school; he used to have to ride for an hour each way.

AWARD

Joseph has participated in the music program, the science fair and fund-raisers. He joined his classmates when they read stories to kindergartners. He is a member of the student council. Recently, he participated in the McDonald's speech contest using a voice synthesizer.

At his last annual review, loseph's classroom teacher stated that the past year was rewarding for both Joseph and his classmates. Though originally reluctant to have Joseph leave the center-based program, his mother now feels the transfer to his home school was for the best.

> Nominated by Helen Magas, physical therapist; Susan Wolthuis, occupational therapist: and Susan Maston, teacher-consultant



ed settings for students with mild and moderate disabilities have found more behavioral progress and increased social competence in inclusive settings, but limited differences in academic performance.

A study by Jenkins and colleagues, done in 1992, was one of those summarized in Nisbet's report to the President's Committee on Mental Retardation. Jenkins used a standardized test to compare students with learning disabilities in two similar schools. One school served students in the regular classroom; the other used a resource room "pullout" model. Results showed that students receiving all services in the regular classrooms made significantly higher overall gains.

Affleck and colleagues also compared student achievement in integrated versus resource programs. They found only slight measurable differences, however, those differences favored the integrated settings. Deno and colleagues report similar results in a 1990 study. They found that while students with mild disabilities served full-time in a regular class progressed more slowly than their peers without disabilities, they still progressed more rapidly than similar students served in pullout programs.

# Are students with significant disabilities successful in inclusive classrooms?

Again, studies generally report more favorable social and behavioral outcomes for students with significant disabilities served in inclusive settings. Because most of these students are not included in standardized testing, academic performance is harder to compare, however, several studies report greater achievement of IEP objectives in inclusive settings.

There are several important studies comparing outcomes for students with significant disabilities served in inclusive placements compared with segregated settings. For example, Ferguson found that students served in an inclusive placement had greater success in achieving IEP goals than did similar students in traditional programs; Burello

and Wright reported gains in student self-esteem; and Marwell reported greater acceptance by peers without disabilities. Other researchers report greater behavioral progress, greater social competence and at least equivalent academic success in inclusive versus segregated settings.

In two studies, Hunt and colleagues found that students in inclusive classes had IEPs containing more references to effective instructional methods than did students in segregated classes. The researchers also found that students in inclusive settings were more likely to interact with other people in the classroom.

# Are inclusive preschool programs successful for students with disabilities?

Nisbet's summary of the research concludes that integration has positive effects on the social competence of preschoolers with disabilities. They spend more time playing and verbalizing in positive interactions with peers. Integration opportunities also appear to have positive effects on other behaviors, for example, increased sophistication of play.

Nisbet adds that integrated and segregated settings seem to be equal in terms of measured developmental progress on standardized tests, negating any argument that segregated settings can provide more specialized and effective interventions. Finally, studies report no negative outcomes for "typical" preschoolers attending programs that include students with disabilities.

# Are inclusive education programs successful for students without disabilities?

A recent research review by Staub and Peck addresses three common concerns related to students without disabilities.

- Slower academic progress? Studies consistently find no slowing of academic progress for students without disabilities in inclusive classrooms.
- Less attention from teachers? Studies showed that the presence of students with severe disabilities had no effect on

continued on page 38

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continued on page 39



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continued from page 37

the amount of teacher attention received by students without disabilities. Furthermore, there was no difference between inclusive and noninclusive classrooms in terms of instructional time lost to interruptions. • Learning of undesirable behaviors? Evidence indicates that students without disabilities do not acquire undesirable behaviors from peers with disabilities. On the contrary, Staub and Peck identified several positive benefits for these students, including increased comfort with and awareness of human differences, improvements in self-concept and the development of warm and caring friendships.

Helmstetter, Peck and Giangreco reported on a statewide (Vashington) study of high school students without disabilities showing more positive outcomes associated with increased contact and interactions with students with disabilities. These outcomes

included increased responsiveness to the needs of others, valuing relationships with people with disabilities, increased tolerance of other people, development of personal values and increased appreciation of human diversity. Several other studies confirm these positive benefits.

### What is necessary for inclusive education programs to be successful?

NCERI's 1994 national study of inclusion programs found the following keys to success: visionary leadership, collaboration between general and special education, refocussed use of assessment, supports for staff and students, funding that followed the child and effective parental involvement.

For school personnel, systematic staff development and flexible planning time for special- and general-education teachers to work together are

essential. For students, supports for inclusive education may include cooperative learning (students at different ability levels work together on a common learning task), curriculum adaptations, "hands-on" learning, multilevel instruction (the teacher provides instruction on the same subject, but at different levels, to students of differing abilities), provision of needed therapy services in the regular classroom, peer tutoring and support, buddy systems, effective use of assistive technology and the availability of classroom aides.

Inclusive education does not mean that all services are always provided in the regular classroom; for example, training in Braille and mobility techniques for a student with a visual impairment may require time in a special setting. But inclusion means that the student's basic placement is in the regular classroom and that the class-

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room teacher is trained to support the student's special training in Braille and mobility.

Does inclusion place too great a burden on general education teachers?

When teachers are provided with appropriate supports, their experiences are positive. This is confirmed by the studies done by Burello & Wright, the Michigan Department of Education, Giangreco and colleagues, Rainforth, and York and colleagues. Other studies (Chase & Pope, Christmas, McDonnell & colleagues) show that when needed supports are not provided—not surprisingly—teacher attitudes are less positive.

What about costs?
The data on special education funding are complicated and the answers not yet clear. The best data come from the federally-funded Center for Special Education Finance, which reports that current funding patterns create incentives for segregated education and disincentives for integrated education.

Districts that have fully-implemented inclusive programs report that, on average, these programs are no more expensive than segregated programs, and perhaps, are less expensive. As researchers McLaughlin and Warren point out, when the costs of providing services in local schools are compared with the costs of transportation and educational services in other settings, inclusion appears to be less expensive. However, for districts to experience actual savings, dollars spent on segregated education would have to be transferred to the home schools of newly-included students with disabilities.

Is inclusion appropriate for all students?
The law recognizes and common sense tells us that each child is unique. Educational research cannot identify what will be best for the individual child. The decision about inclusion, or any other educational option,

must be made individually—in light of the law, an understanding of relevant research and the family's values.

The law shows a clear preference for inclusion. (See "The Law and Inclusion," page 40.) As the court stated in *Oberti*, "Inclusion is a right, not a privilege of a select few." The decision went on to state that a school district may not place a child with disabilities outside of a regular classroom "if educating the child in the regular classroom, with supplementary aids and support services, can be achieved satisfactorily."

NCERI's 1995 study of inclusive education programs reports on nearly 900 school districts across the country that are successfully educating students with all types of disabilities—at all levels of severity—in inclusive classrooms. And a Michigan Department of Education study, after reporting on research data showing a strong trend toward improved student outcomes in inclusive settings, adds, "One must seriously question the efficacy of spending ever-increasing sums of money to maintain dual systems." **EP** 

Dorothy Kerzner Lipsky, Ph.D., the parent of a 26-year-old son with spina bifida, is director of the National Center on Educational Restructuring and Inclusion (NCERI) at The Graduate School and University Center, The City University of New York, where Alan Gartner, Ph.D., is the dean for research. They are co-editors of BEYOND SEPARATE EDUCATION: QUALITY EDUCATION FOR ALL (Paul H. Brookes, 1989) and co-authors of Supporting Families with a Child with A DISABILITY: AN INTERNATIONAL OUTLOOK (Paul H. Brookes, 1991). Both books can be ordered by calling (800) 638-3775.

The NCERI BULLETIN is available at no cost. The NCERI 1995 STUDY OF INCLUSIVE EDUCATION AND EDUCATIONAL RESTRUCTURING may be purchased for \$15, prepaid. Both are available from NCERI, The Graduate School and University Center, The City University of New York, 33 W. 42nd St., Rm. 1530, New York, NY 10036.

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# The Law and Inclusion

by Barbara Ebenstein



he Individuals with Disabilities Education Act (IDEA) encourages school districts to educate children with disabilities in regular classrooms. The IDEA uses the term "least

restrictive environment," meaning that "to the maximum extent appropriate," children with disabilities should be educated with children who do not have disabilities, and that "special classes, separate schooling or other removal of children with disabilities from the regular educational environment, occurs only when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."

Unfortunately, this language leaves many questions unanswered: When is inclusion appropriate? What supplementary aids and services are reasonable in a cost-conscious school district? When can one conclude that inclusion cannot be achieved satisfactorily? And whose satisfaction are we talking about? Parents and school districts often disagree on these points.

### When parents and school districts disagree

Parents who do not agree with the school district regarding a child's evaluation, classroom placement or IEP (Individual Education Plan) can turn to legally-established due process procedures referred to as "administrative remedies." The first of these is an "impartial hearing," which is like a miniature trial in which both sides present witnesses and evidence, including reports of the child's past classroom experiences, to a hearing officer. The hearing officer acts as judge and renders a written decision.

Either side—the school district or the parents—can appeal this decision to the review officer in the state's department of education. After reviewing the electronic or written record of the hearing, the evidence that was presented and the decision of the hearing officer, the state review officer will issue a written decision about the case.

This decision signals the end of "administrative remedies." Most grievances are resolved by this point. However, if the parents or representa-

1995

EDUCATION

AWARD

tives of the school district remain dissatisfied, they can seek judicial review of the case in the federal courts.

This process begins by filing the case in federal district court, which holds a full trial and renders a decision.

Next, either side may appeal to the federal circuit court for the region that includes their state or U.S. territory (see sidebar, page 42). The circuit court will review the transcript of the district court trial, the evidence presented and the decision rendered. Lawyers for both sides submit written briefs (documents summarizing the issues and pertinent laws) and present oral arguments. After a decision is rendered, the case may be appealed to the U.S. Supreme Court, however, very few such cases are accepted for review.

Because the U.S. Supreme Court has not directly addressed the issue of inclusion, each federal circuit court must set ils own criteria for determining when inclusion is appropriate. A circuit court decision sets a precedent to be followed in the states within the court's jurisdiction. Lower courts in jurisdictions where there has been no circuit court precedent are influenced by opinions from other jurisdictions.

To know the criteria a school district should use to determine whether inclusion is appropriate for a particular child, one must be familiar with the precedent followed by the federal circuit court in that jurisdiction. This is important information for parents to have-whether they want their child included or are advocating for a more segregated placement.

"Mainstreaming" and academics

In 1980, the U.S. Supreme Court reviewed an IDEA case brought by the parents of Amy Rowley, an eight-yearold who was deaf, and who attended her local elementary school. Amy's parents wanted a sign language interpreter in Amy's classroom. Although inclusion was not at issue in this case, the Court's decision stated that a child with a disability, who was being educated in a

# Fox Chapel Area High School, Pittsburgh, Pennsylvania

When you walk into classrooms at Fox Chapel Area High School, you can expect to see students moving in and out of learning groups and to hear teachers coaching and giving feed-

back to the students. But don't expect to be able to tell which students and teachers might be labeled "special education."

The divisions between regular and special education aren't obvious here. Instead of special education, we provide educational support. Support teachers—formerly called special education teachers—team up with content-area teachers each day to provide instruction to groups of students with diverse learning abilities. In co-taught classes, support is available to any student who needs it.

Here is what support at Fox Chapel looks like: In a social studies class you may see a cooperative learning group clustered in a corner working on a map project. A second teacher is going over yesterday's homework with students seated around a table. As you walk into a math class, you may see several students working on a computerassisted math assignment, while next door, another math teacher is working with four students from the same class, providing a mini-lesson on measuring volume.

Through team-teaching and adapted instruction—including adapted study materials and testing—Fox Chapel Area High School has succeeded in creating a comprehensive inclusion program that addresses the diverse needs of all its students.

Nominated by Lynne Porterfield, coordinator of special education

regular classroom, would be expected to work on grade level and progress from grade to grade with the rest of the class. The *Rowley* case validated the existence of two separate educational systems—one segregated system and one regular system in which children with disabilities who could perform on grade level were mainstreamed. This meant that most children with disabilities were placed in segregated classes, and "mainstreamed" only for music, art or physical education.

### Relaxing academic standards

In 1989, an important circuit court case relaxed the requirement that a child with a disability must be able to work on grade level to be included in a regular classroom. The parents of Daniel R., a six-year-old with Down syndrome, wanted their son placed in a regular classroom in Texas. The Fifth Circuit Court ruled that there could be some modification of the curriculum to accommodate Daniel's special needs. The court stated, "We cannot deny the child access to regular education simply because his educational achievement lags behind that of his classmates," but added that "mainstreaming would be pointless if we forced instructors to modify the regular education curriculum to the extent that the handicapped child is not required to learn any of the skills normally taught in regular education." This court envisioned mainstreaming as appropriate for children who could master at least some of the regular curriculum.

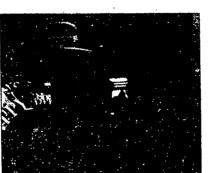
As part of the Daniel R. decision, the court developed a "test" still widely used to determine "the least restrictive environment" appropriate for a particular child. This test requires a school district to weigh four factors in determining whether a child can receive an appropriate education in a regular classroom; 1) the educational benefit to the child, 2) the non-academic benefits to the child, 3) the potential disruption to the classroom and 4) the cost of the placement with all necessary supplementary aids and services. The school district must make reasonable efforts to accommodate the child in a regular classroom-not "niere token gestures"-but if the child cannot be

# Steinmetz Academic Center, Chicago, Illinois

Mrs. Jackie Williams once feared a phone call from the administration of Chicago's Steinmetz Academic Center suggesting she find another placement for her son, Carl, because of his disabilities. That call never came. Instead, she celebrated her son's success after his return from the state capitol, where he and other students from Steinmetz had presented a play focusing on the gifts and talents of a diverse school population in an urban milieu!

The following factors have led to the success of the teaching and learning process at Steinmetz:

- An "all-means-all" commitment from the principal, Dr. Constantine Kiamos; assistant principal, Dr. Arthur Tarvardinan and Steinmetz staff.
- A collaborative team approach with input from parents, staff and central office



"Birthday boy" Curtis Mitchell (left), a student at Steinmetz High School, gets a squeeze from a pal.

support staff.

• An absence of "road blocking" behaviors and attitudes: the entire team focuses on opportunities rather than limita-

• A proactive parent advocacy group focusing on the needs of children.

Because Steinmetz Academic Center values flexibility and has never believed in maintaining the status quo for its own sake, the school can adequately address the needs of its students as they present themselves in the proverbial "teachable moment."

Nominated by Charlene Green, associate superintendent for special education and Greg Stricklerpoe, senior adviser for inclusive schools

placed in a regular classroom, the school district should integrate the child into regular school activities whenever possible.

In this case, evidence showed that Daniel was unable to master any part of the curriculum, and that his need for constant attention disrupted the class. The court ultimately permitted Daniel to be placed in a self-contained special education class. The *Daniel R*. test sets a precedent that *must* be followed only in Texas, Louisiana and Mississippi, however, it has influenced cases in other jurisdictions.

One such case was brought by the parents of Christy Greer, a 10-year-old with Down syndrome. Applying the Daniel R. test, the Eleventh Circuit Court decided that Christy's school district in Georgia had not made a sincere effort to accommodate her in a regular classroom. The court ruled that the district must consider all supplementary aids, services and curriculum modifications that could facilitate Christy's inclusion. Christy's school district was ordered to place her in a regu-

lar classroom. The Greer case sets a precedent that must be followed in Alabama, Georgia and Florida.

### Inclusion for all?

More recent cases have encouraged the inclusion of children with disabilities even if they cannot master any gradeappropriate curriculum. For many people, this differentiates "mainstreaming" from "inclusion." The parents of Rafael Oberti, an eight-year-old child with Down syndrome, wanted their son fully included in a regular classroom in New Jersey. Due to the severity of Rafael's disability and his history of disruptive behavior, the school district proposed placement in a self-contained classroom. In a lengthy trial, educational experts discussed a variety of accommodations including a resource room, curriculum modification and 'parallel instruction," which would permit Rafael to work on an activity beneficial to him while the rest of the class worked on a different activity.

Following the  $Daniel\ R$ . test, the court ordered Rafael's inclusion without

- continued on page 42



SEPTEMBER 1995 / EXCEPTIONAL PARENT • 41

considering the cost of accommodations, because neither side raised the issue. The *Oberti* case is important not only because it provides a precedent in New Jersey, Pennsylvania and Delaware, but also because the U.S. Department of Education based its position paper on inclusion on this case.

In a similar case, the parents of Rachel Holland, a nine-year-old girl with a developmental disability and a tested IQ of 44, wanted her included in a regular classroom in California. The Ninth Circuit Court, applying the *Daniel R*, test, determined that Rachel should attend a regular classroom with additional services. Unlike *Oberti*, the court considering *Holland* was asked to consider the cost of including Rachel, and found that the Sacramento school district had exaggerated these costs.

Rachel's school district also asked the court to consider the extent to which the curriculum would have to be modified for Rachel. However, the court found that the need for curriculum modification is implied by the IDEA. The *Holland* decision sets a precedent that must be followed by lower courts in Alaska. Arizona, California, Hawaii, Idaho, Nevada, Oregon, Utah, Washington and the U.S. territories of Guam and the Northern Mariana Islands.

### Variation in inclusion criteria

As discussed above, four federal circuit courts—the Third, Fifth, Ninth and Eleventh Circuits—have established inclusion criteria based on the *Daniel R*. test. Most school districts in the 21 states and territories within these four circuit court jurisdictions use the *Daniel R*. test as applied in *Oberti* and *Holland*.

The Sixth Circuit Court uses a different standard based on an earlier case in which a school district in Ohio recommended that Neill Roncker, a nine-yearold with severe mental retardation, be placed in a special county school. His parents, however, wanted Neill educated in a self-contained class in a regular school where he could have opportunities-during lunch and recess-for interaction with peers who did not have disabilities. The school district contended that any small benefits Neill would receive from this "mainstreaming," would be outweighed by the academic benefits of the special school.

The court's decision stated that if placement in a segregated facility is considered superior for a particular

child, the school district must determine whether those services that make that placement superior could be provided in a regular school. If so, the regular school is the appropriate placement. In such cases, school districts must consider the following factors: the benefits derived from services that cannot be provided in a regular setting, the disruption caused by inclusion of the child and cost. The Fourth and Eighth Circuit Courts also have applied the *Roncker* test.

### Conclusions

Inclusion is merging the two previously separate educational systems mentioned by the U.S. Supreme Court in the Rowley case into one comprehensive system for most children. Determining the appropriate placement for a particular child always involves an analysis of his or her unique abilities, disabilities and special needs. Potential benefits to the child are balanced against the potential burden to the school district. The outcome depends on the specific facts of each case, and often depends on the child's age and disability. Courts have ordered the inclusion of young children with Down syndrome and other developmental disabilities, while

# Syracuse City School District, Syracuse, New York

The Syracuse City School District believes that team-teaching is the best way to offer appropriate supports to students in inclusive classrooms. Each inclusive classroom is staffed with

a regular education teacher, a special education teacher and a special education teaching assistant. Each class includes six to eight students with special needs, with approximately 25 "typical" students. No entrance criteria or disability category excludes students from inclusive classrooms.

Currently, 50 elementary class-rooms in 13 different schools are full-day inclusive settings. Two middle schools have inclusion teams—comprised of about 110 typical students and eight to 12 students with special needs—at the seventh- and eighth-grade levels. One high school in Syracuse has offered an inclusive program for three years to approximately 85

students who would have been assigned to self-contained classrooms.

I was visiting this high school one day when a student with special needs, who had been in the inclusive 1995 EDUCATION AWARD

program for four weeks, stopped me and said, "Now that I'm not in special education anymore, do I still have to ride the yellow school bus to school?" In Syracuse high schools, students with special needs, who can't handle public transportation, ride traditional yellow school buses. Within the last four weeks, this student's selfesteem had risen to such a degree that he no longer considered himself a special education student. Of course, Limmediately took his name off the yellow bus route and made sure he was given a bus pass.

> Nominated by Edward Erwin, director of special education



For students at Salem Hyde Elementary School, part of the Syracuse City School District, "sitting in the corner" means an opportunity to learn.



older children and those with high management needs are usually placed in segregated settings.

Some school districts are now experimenting with full inclusion for all children with disabilities. Done properly, inclusion should cost a school district as much as self-contained special education, but some districts try to save money by including children without providing sufficient supplementary aids and services. Some parents of included children are dissatisfied with the training of regular classroom teachers and the attitudes of other children. Parents of more than 300 children with learning disabilities in Maryland brought suit to prevent the inclusion of their children. The court dismissed the case because the parents had not yet exhausted their administrative remedies. But in the future, more parents may properly file "reverse-inclusion" cases, in which they ask to have their children placed in more segregated settings while their

school districts propose full inclusion. These parents will argue that although inclusion is the "least restrictive environment," it does not meet the IDEA's requirement of an "appropriate" education for their children.

Inclusion is an emotionally charged issue for parents. It touches on the severity of the child's disability, as well as the child's future assimilation into the community. One mother told me, "my son used to be disabled; now, he is included." This statement is either a tragic misconception of the nature of disability or a profound statement of the potential of inclusion. **EP** 

Barbara J. Ebenstein is a partner in the law offices of Ebenstein & Ebenstein in New York City. She lives with her husband, Dr. John E. Handelsman, and their three daughters, Saruh, 14, Leanne, 12, and Risa, 9, who has a neurological impairment.



**1st Circuit:** Maine, Massachusetts, New Hampshire, Rhode Island, Puerto Rico

2nd Circuit: Connecticut, New York, Vermont

**3rd Circuit:** Delaware, New Jersey, Pennsylvania, Virgin Islands

4th Circuit: Maryland, North Carolina, South Carolina, Virginia, West Virginia

5th Circuit: Louisiana, Mississippi, Texas

**6th Circuit:** Kentucky, Michigan, Ohio, Tennessee

7th Circuit: Illinois, Indiana, Wisconsin

8th Circuit: Arkansas, Iowa, Minnesota, Missouri, Nebraska, North Dakota, South Dakota

9th Circuit: Alaska, Arizona, California, Hawaii, Idaho, Montana, Nevada, Oregon, Washington, Guam, Northern Mariana Islands

10th Circuit: Colorado, Kansas, New Mexico, Oklahoma, Utah, Wyoming

11th Circuit: Alabama, Florida, Georgia





Circle #180

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# Making a Good Law Better

IDEA proposal stresses greater parental involvement and student inclusion

by Judith E. Heumann



his past summer, the Clinton administration introduced to Congress a proposal for reauthorization of the Individuals with Disabilities Education Act (IDEA). This marks the

first substantial revision to the law since 1975, when Congress enacted Public Law 94-142, the basis of IDEA.

The proposal was the result of a year and a half of careful study, thorough reexamination and intense analysis by my staff at the U.S. Department of Education's Office of Special Education and Rehabilitative Services (OSERS). During this process, we consulted with some 3,000 educators and parents of students with disabilities.

The proposal demonstrates our commitment to ensuring that equality of educational opportunity is more than a rhetorical slogan. We want it to become a daily reality for every student in America—those with disabilities and those without. As Secretary of Education Richard Riley says, "America cannot afford to waste the talents, knowledge or skills of a single individual."

The IDEA proposal is a key part of President Clinton's package of national disability policies, based on "inclusion, not exclusion; independence, not dependence; and on empowerment, not paternalism."

### Closing the gap

IDEA has proven to be an extremely effective law. A recent Louis Harris survey report states that "...largely due to the IDEA, the gap in education [between students with disabilities and those without] is beginning to close."

Are we satisfied? No! Too many students with disabilities are still failing courses and dropping out of school. Their enrollment in post-secondary education is low, and too many are leaving school not fully prepared for employment and independent living.

I believe we should continually raise our expectations for special education. We can and should adjust the IDEA to meet the changing needs of the 21st century.

Strengthening the IEP process
The most important parts of our IDEA

reauthorization proposal are changes intended to strengthen the IEP (Individual Education Plan) process and to encourage the early and continuous involvement of parents. Under our proposal, students with disabilities are to be taught the same general curriculum as students without disabilities, or parents must be told why not. We want students with disabilities to be able to meet the same challenging standards established by states and communities for children without disabilities.

1995

EDUCATION

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# Jefferson County Public Schools, Jefferson County, Alabama

Inclusion is a "hot topic" in special education, and rightly so. Most discussions about inclusion, however, focus on the school—team teaching, use of para-professionals, modifications in the regular classroom.

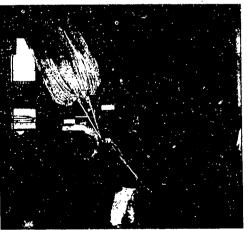
But isn't the least restrictive environment truly found only in the real world—the community? The Jefferson County School System embraces this broader view of inclusion. Junior and senior high school students with moderate to severe disabilities are beginning to participate in community based instruction (CBI), in

which students leave the school setting, become active participants in their community and learn to perform real-world skills. Successfully performing skills accomplishes many goals of inclusion by improving academic achievement, self-esteem, parental expectations and community acceptance of students with disabilities.

CBI not only teaches our students with disabilities to function in the real world; it also teaches the real world about people with disabilities. The community comes to view students with disabilities as prospective employees, and people willingly offer their businesses as work assessment sites.

With an inclusionary view of inclusion, we as educators will be more effective in offering students with disabilities opportunities to enhance their quality of life.

Nominated by Penny Ray, supervisor of exceptional education



Jefferson County's comprehensive view of inclusion includes work experience in the community. In this photo, student Jimbo Karr works in a local laundry.

## Six principles

Our proposed IDEA improvements are based on six key principles, with strategies to implement each:

- Align IDEA with state and local education reform efforts so students with disabilities can also bruefit. Connecting IDEA programs with educational improvements occurring in schools around the nation would help ensure that all children are included in school improvement activities. "Special education" would be seen as supports and services rather than separate programs and places.
- Improve results for students with disabilities through higher expectations and access to the general curriculum. in the least restrictive environment. A child's IEP would focus on his or her participation in the general curriculum and methods of evaluating his or her progress and educational program.

As before, members of the IEP team would include the child's parents and special education teacher. In addition, our proposal would mandate the participation of at least one regular education teacher, if the child is now or is likely to be in a regular classroom. Parental input would be an important part of developing the IEP and determining measurable annual objectives.

Importantly, IDEA would now require that parents receive reports on a child's progress on a regular basis—by such means as report cards—at least as often as reports are issued to the parents of students without disabilities in the school. These reports will allow parents to judge the success of the child's IEP and determine whether modifications are needed.

The IEP would have a greater focus on what is necessary to ensure successful inclusion--the services and supports needed for the child to learn to high standards, in the same curriculum used for all children, to the maximum extent possible. It would also describe the special education, related services and program modifications a child needs to meet annual IEP objectives, to participate in the general curriculum and to take part in extracurricular activities.

Moreover, it would justify the extent—if any-to which a child will not be educated with students without disabilities.

A critical new addition to IDEA would be that children with disabilities, with few exceptions, would participate in state and district-wide assessments. Recognizing that a small number of students with significant cognitive disabilities cannot be included in regular assessments, the IDEA would require alternative assessments in order to measure the performance of these students. Results for all students with disabilities, such as state assessments, would be publicly reported, thus ensuring more accountability for educational results.

Transition planning would begin when a child turns 14. This planning would consider the course of study and supports needed to move toward postsecondary education, employment or other meaningful activities.

· Address individual needs. A child's initial evaluation and three-year reevaluation would be more likely to include information to help parents and teachers judge the effectiveness of various teaching methods. Once it is determined that a child has a disability, the currently required reevaluation would no longer have to include a full battery of tests to determine whether the child continues to have a disability, as long as both the parents and the school agree these tests are unnecessary.

The current procedure of making educational decisions based solely on a child's disability category is contrary to what research shows and parents know-that each child has unique needs, regardless of his or her disability category. To promote eligibility determinations that focus on educational needs, states would be allowed to use eiigibility criteria that are less categorical. This means that criteria used to determine eligibility for special education could focus more on needs and less on diagnostic labels, while ensuring that all students who are currently eligible, remain eligible. Of course, parents would still have the right to challenge eligibility decisions made by school districts.

Changes in the IDEA funding formula

would encourage states to do early intervention and prereferral activities. It would be easier for a child's school to provide special education services in the regular classroom because the excessive paperwork now required to track the use of IDEA funds would be eliminated. And the elimination of "labels" would discourage the over-identification of children for special education, helping schools better serve all students.

• Provide families and teachers—those closest to students-with the knowledge and training to

effectively support students' learning. Too often today, parents get notices that are too long and too full of "legalese." To help parents understand the issues included in the notices, we propose improvements to the notice requirement to ensure that parents get better, more useful information. Importantly, par-

WE CAN AND SHOULD **ADJUST THE** IDEA TO MEET THE CHANGING **NEEDS OF** THE 21ST CENTURY.

ents would be part of the child's placement team, a right not previously mandated by federal law. Thus, they would have a right to participate in this critical decision about their child's education in those states that do not now provide for their participation.

In addition, in order to help resolve disputes in a "parent-friendly" manner, states would be required to offer parents mediation as an option for resolving any complaints parents might have with their child's school. However, parents would continue to have the option to request a hearing.

We would promote state and community partnerships to meet the educational, health, mental health and social service needs of children and their families.

The Department of Education is an

continued on page 46

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### IDEA PROPOSAL

continued from page 45

important clearinghouse of information about practices that have proven effective for families, schools and communities. To help make the best information about what works available, we would make a coordinated effort to do research on key issues and make information available to those who want it.

We also know that trained teachers and other professionals are vital to student success. Therefore, the federal government would make funds available to states to develop statewide plans for professional development. This would assure that those who work with children with disabilities would be appropriately trained. To help parents support their children's learning and understanding, a parent training and information center would be required in every state.

• Focus resources on teaching and learning. Because unnecessary paper-

work would be eliminated, teachers and administrators could focus more effectively on educational activities.

Schools would have greater ability to maintain safe and disciplined class-rooms. A student who brings a firearm or other dangerous weapon to school could be moved to an alternative setting. Also, hearing officers would be permitted to place in an alternative setting students who are substantially likely to injure themselves or others. These alternative placements could last up to 45 days, during which time the IEP team would consider appropriate services and placement for the student.

• Strengthen early intervention services. Infants and toddlers at risk of developmental delay would be more likely to receive early intervention services because states would have the option of providing service coordination only to these children. As a result of the recommendations of a panel of

experts, less variation in the definition of "developmentally delayed" could exist from state to state.

### Every child is different

I believe our society should provide the resources necessary to allow each individual child—those with and without disabilities—to succeed in school and to prepare for a productive, fulfilling life. The specific resources needed, and the combination in which the resources are needed, will be different for each child, because each child is different. **EP** 

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Department of
Education.



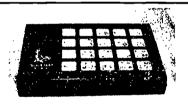
# DRESSING TABLE

for your convenience



- · dress, change and bathe your child at the right working height
- · saves your back
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Circle #26

# 1995 EXCEPTIONAL PARENT Education Awards: Honorable Mention





The Betsy Ross dance troupe gave a special performance based on Dieney's "The Lion King." Troupe member Ketie, 12, (front right) has Down syndroms.

• Betsy Ross School, Anaheim, California: Children in special education classes are involved in all educational and after-school activities, including a pageantry troop, dramatic productions and an ongoing Special Olympics training program. Sixth-grade students with disabilities are looking forward to attending a week-long science camp this fall with sixth-graders who do not have disabilities. Nominated by Larry Herschler, special education teacher.

- Daniel Webster Middle School, Waukegan, Illinois: Daniel Webster Middle School has an in-class model of service delivery for students with learning disabilities (LD) included in regular class-rooms. An aide helps each student meet the demands of the regular class, and resource periods offer additional support. Nominated by Will Guilianelli, coordinator of special education for learning disabilities.
- Jenks Public Schools, Tulsa, Oldahoma: Each school in the Jenks district has an inclusion team consisting of staff representing regular and special education. "Circle of friends" clubs and peer-tutor

programs promote student understanding and acceptance of individual differences. Nominated by Janet Ellsworth, director of special education.

• L.P. Brown Elementary, Olympia, Washington: Children with disabilities participate fully in age-appropriate classrooms and within the school community. General and special education teachers provide learning experiences that build on each child's strengths and needs. Nominated by Stillman W. Wood, assistant superintendent and Paula Akerlund, director of special services.



Miller Middle School teachers Marilyn Dysart (left) and Karen Allen (right) help students build molecular models. Teaching pairs are an important part of Miller Middle School's "cooperative classes."

• Miller Middle School, Marshalltown, Iowa: Miller Middle School) has more than 40 "cooperative" classes offering special education services in a regular classrooms. Complimenting cooperative classes, Miller Middle School has an education center where special education professionals offer homework assistance. Nominated by Brad Clement, principal.

continued on page 48

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Circle #262

Circle #122

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SEPTEMBER 1995 / EXCEPTIONAL PARENT + 47

Stephen Royers, 8, a student with Down syndrome, spends his recess at Oak Mountain Elementary "hanging around" with friends.

• Park School, Evanston, Illinois:

The curriculum at this centerbased school emphasizes oft-

training and money manage-

training to develop skills for

future employment. A job pro-

gram places students into com-

munity job-training positions.

Nominated by Judy Alonso, president, Park School PTA.

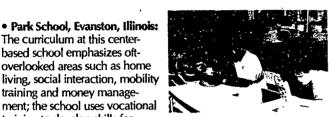
overlooked areas such as home

ment; the school uses vocational

# 1995 EXCEPTIONAL PARENT Education Awards: **Honorable Mention**

continued from page 47

 Oak Mountain Elementary School, Shelby County, Alabama; As part of an inclusive-education pilot program, 67 students with disabilities were fully included in regular classrooms. The program's success led to Oak Mountain Elementary's selection as a state model demonstration site for inclusive education. Nominated by Kathy Snyder, early childhood special education program specialist.



Students in a Park School home living course learn about various components involved in house manage-

 Signal Hill Elementary School, Voorhees, New Jersey: Signal Hill Elementary enabled Crystal, an 11-yearold girl with Werdnig-Hoffman disease who lives at Voorhees Pediatric Facility. to progress academically and socially. Crystal, accompanied by a full-time nurse, changed classes with her peers for music and gym-and received special education for other classes, including reading and math. Nominated by Lisa Baldwin Piccolo, Voorhees Pediatric Facility social work coeffinator.

• Wendell Elementary, Wendell, Idaho: This early childhood educational program provides services to three- to fiveyear-old children with developmental delays, Integration opportunities are provided by bringing children without disabilities into the preschool setting. Nominated by Margo Sears, parent, and Brenda Hall, pre-school teacher.





Twelve-year-old Crystal accepts her graduation certificate from Bernadette Gorman, special education teacher at Signal Elementary School.

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# In Defense of Educational Choice

n April 14, 1977, Jim and Connie Roberts learned that their youngest daughter, 18-month-old Katie, was profoundly deaf. Connie remembers the date clearly, because Jim, an accountant, took the day off so he could be there when Katie was

tested. Connie laughs about that detail now, "I think the only legitimate reason for a CPA to take time off the day before tax deadline is a funeral—preferably their own."

Like other parents of a child with a newly-diagnosed disability, Jim and Connie started looking for answers. They were given plenty of "solutions," Connie recalls, "each in conflict with the

other. All-or-nothing philosophies, messages that said, 'Follow us, or your child is doomed to failure.'"

Below: During her senior year at the Model Secondary School for the Deaf (MSSD), Katie toured the U.S. and Europe with MSSD's performing arts "road show troupe."



Above: Katie Roberts, 10, spent fourth grade in a regular classroom with an interpreter at the Oscar Howe Elementary School in Sioux Falls, South Dakota.



In response, Jim and Connie decided to come up with their own goals for Katie, goals that could be used to evaluate potential educational methods and placements. Their list of objectives included positive self-esteem, responsibility, independence, social skills, becoming a life-long learner. "Not exactly IEP goals," says Connie, but "life goals" that would require a strong academic program.

By the time Katie was ready for kindergarten,

her parents realized that no single available program could meet all her academic and social needs. Their solution was to work out an arrangement that allowed five-year-old Katie to spend half-days in a classroom at the South Dakota School for the Deaf (SDSD), and half-days in a regular kindergarten classroom with an interpreter—"the first classroom interpreter in the Sioux Falls public schools," Connie adds.

Katie's educational program continued to change with her needs. She was fully mainstreamed for most of elementary and junior high school; in high school, she returned to a "split-day" program. dividing her time between SDSD and the same Catholic school her older siblings attended. To have a more complete social life, she spent school weeks living in the dorm at the school for the deaf. Then, in the middle of her sophomore year. Katie transferred to the Model Secondary School for the Deaf, on the campus of Gallaudet University in Washington, DC (where she now attends college). "Allowing that move was difficult," says Connie, "but we realized we could not create an environment for her here that could meet all her social, emotional and academic needs."

"More than we could provide at home"
Kimberly Donovan, 22, who has mild mental retardation and developmental aphasia, has been a residential student at the Cardinal Cushing School and Training Center, a program of St. Coletta's of Massachusetts, since 1987. Before that, she attended several public school programs. Her father, Jerry, says, "I know the trend today is to include all kids in the regular classroom. That's fine for some students—but not Kim. She needed the kind of individual attention she couldn't get in a regular classroom."

Cardinal Cushing provided an excellent academic program, says Kimberly's mother, Jackie, who is particularly proud that Kim defied "expert" predictions and learned to read. But the residential program had other benefits, too. Through participation in Girl Scouts, school plays, special-interest clubs and cheerleading, Kim's social skills grew tremendously. "When Kim first entered the school," Jackie explains, "she related only to adults. Over the years, she has learned to communicate with and relate to her peers. She's made friends. Those 'fun' activities at school gave

continued on page 52



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her so much more than we could have provided at home."

### Defining "LRE"

The Donovan and Roberts families worry that advocates of a one-size-fits-all approach to education will rob today's parents of the range of placement options their children enjoyed.

These concerns are echoed by attorney Lawrence Siegel, author of *Least Restrictive Environment: The Paradox of* 

Kimberly Donovan, 22, celebrated her June 1995 graduation from Cardinal Cushing School with her parents, Jackie (left) and Jerry.

Inclusion (LRP Publications, PO Box 980, Horsham, PA 19044-0980; 800/341-7874, ext. 275; \$32, incl. shipping). "The IDEA [Individuals with Disabilities Education Act] is a good law, basically," Siegel says, "but it has two problems. First, it calls for placement in the 'least restrictive environment'—or 'LRE'—but at the same time, requires the provision of an 'appropriate education.' Courts have recognized that the I.RE requirement is sometimes in conflict with the 'appropriate' requirement.

"Secondly, the LRE requirement itself is very confusing. Many people think of LRE as a *place*, when, in fact, LRE is a *process*. Courts have stated that the regular classroom is the LRE for some children; but in other cases, they have been equally clear that a state school can be the LRE."

Siegel has represented parents who wanted their children included, as well as those who wanted their children moved from regular classrooms to more segregated settings. "I feel very strongly that we need to look at individual children and their individual needs," he says. "It is ironic that the inclusion movement came about because school systems were making generic decisions about placement—keeping kids out of regular classrooms based solely on their disability category. Inclusion advocates were upset about that—and rightfully so. But now, when some say that *all* children with disabilities should be in regular classrooms, they are doing the same thing to others."

### A focus on individual needs

In the following pages, a number of parents share stories about the educational choices they have made for their children. Running through these very diverse stories are several common threads. One is a belief that placement decisions should be based on the individual child, and his or her unique needs. Another is a profound respect for the choices of others—although these parents have made very different choices, each is careful to avoid making pronouncements about the "right choice" for other parents and children.

Connie Roberts probably speaks for many when she says, "There are no perfect programs, just different options. We can't look at any option as right or wrong; instead, we need to ask how a particular program can meet the needs of children. The program that works best is the one that works best for *your* child."

--Kim Schive

Kim Schive is associate editor of Exceptional Parent.

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Circle # 107 9 0



# Readers Talk About: EDUCATIONAL CHOICES

# Where Do We Go From Here?

S

hortly after Sheila was born, we heard about a conference on inclusion. We went; we listened; we jumped on the bandwagon. It became very important to us that our child with Down syndrome be raised in the same world where the rest

of us reside.

We made sure Sheila spent her preschool



Seven-year-old Sheila Holroyd (right) dressed as a fortune teller for the first-grade Halloween party in October 1994.

years around "typical" children. She attended the Rainbow Express Learning Company, the same nursery school as her older sister—"Of course, we'll take her," director Sandi Hughes told me. "This is one battle you will not have to fight." The school made some accommodations to make it work, but work it did.

By the time Sheila turned four, we had established a track record demonstrating she could be success-

ful in an inclusive setting with proper supports. As a result, our school district was willing to try half-days in the regular classroom with an aide and consulting teacher.

Sheila's first year of kindergarten had its ups and downs. The consulting teacher argued with me constantly; she felt Sheila belonged in a segregated setting. The speech therapist, who told me she had not gone into speech pathology to work with "kids like Sheila," presented another problem. At many of our monthly team meetings she would make comments about Sheila's personality ("She's lazy") or cognitive abilities ("After all, she *is* severely retarded").

I alternated between blinding rage and a depression so deep I would cry for days. By mid-year, when Sheila's classroom teacher went on maternity leave and her aide also left, I had to ask if this placement was the right thing.

But the second half of the year was better.

The new classroom teacher happened to have a background in special education, and Sheila's new aide adored her. With adequate support in the classroom, I was no longer as worried.

The following year, not yet ready to sit quietly for extended periods as required in first grade, Sheila, now 6, repeated kindergarten. With a new consulting teacher, almost everything went smoothly—everything except speech therapy. And unfortunately, speech therapy was becoming more and more important. Sheila, an extremely social child, was still essentially nonverbal and becoming increasingly frustrated.

Should we stop "doing inclusion" because of staffing problems, or should we hold firm to our belief that we all belong together? My husband, Forrest, maintained that holding fast to the ideal was important. I waivered. If only I could convince myself that inclusion is always the best option. "We don't hesitate to create special programs for gifted children," I thought. "Why do we insist an inclusive setting is best for all children with disabilities?"

We decided to "hang in there," and Sheila moved on to first grade. This past year—spent in a first-grade classroom of 28 students—was especially tough. Sheila started demonstrating inappropriate behavior, such as hitting other children. Several teachers recommended having her tested for attention deficit hyperactivity disorder (ADHD), but I was reluctant. Sheila really didn't need another label.

Finally, I discussed it with her pediatrician. After testing, Sheila had a new label and a prescription for medication. Her behavior improved, but she was still easily distracted. We were asked to consider having her spend one period a day in the resource room. Reluctantly we agreed, but we can read the writing on the wall—45 minutes this year; next year, what? Two hours?

But this past year also brought us a new speech therapist and a small miracle—Sheila is talking! It began with one or two new words a day. Now, there are so many I cannot keep track of them. Mrs. Chico, the speech therapist, uses signs and the manual alphabet to cue Sheila's speech. She shows Sheila how to make her mouth form the right shapes to make sounds. If the rest of Sheila's program could get

# Me Invite you to contribute in the identification in future issues of Experience Primal in upcoming months, readers will be talking

- Grandperents/extended family (December; deadline Oct.1,1995)
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Write to: Readers Talk, Exceptional Parent, 209 Harvard St., Ste. 303, Brookline. MA 02146, (617) 730-8742 (fax).





its act together, I would keep Sheila in this school forever—just to work with Mrs. Chico.

We continue trying to make inclusion work. As Sheila begins second grade, I try not to lose sleep over circumstances that are out of my control. I don't know that we could find a school district as willing to try as ours; we continue to hope they will somehow get it together.

But we continue to explore other options.

Where do we go from here? What is best for Sheila? In the coming years, we know we will need to remain flexible so we can find the best ways to give Sheila all the skills she will need to have in the grown-up world.

—Nancy E. Holroyd Duanesburg, New York F ONLY
COULD
CONVINCE
MYSELF THAT
INCLUSION
IS ALWAYS
THE BEST
OPTION.

# A Lesson From the "Inclusion People"

had enormous reservations about sending my child to school. For starters, I knew I did not want him attending a "school for the severely disabled." It wasn't that I preferred to have him integrated into a regular classroom, I just didn't want him labeled "retarded."

Kevin failed the test that would have made him eligible to attend a school for the "orthopedically disabled" and be integrated into regular class-rooms. Nobody labeled him "retarded," but they did say he had "severe developmental delays" and suggested that he attend a school in our area that serves children with severe disabilities.

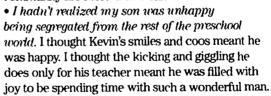
So, with some hesitation, I agreed. I visited the school; I observed the classroom; and yes, I tailed my son's bus to school—but only once.

I discovered I was happy. My son was going to a school where caring and educated people were knocking themselves out on a daily basis to provide Kevin and the other kids with a sound education and solid skills. The school was *alive* with laughter and brightness and progress. There was nothing depressing or dull or uninspiring about it. I loved the school! And more importantly, *Kevin* loved it.

And then I met the "Inclusion People." They are everywhere—I realize that now—but I met mine at a local workshop. They cornered me during the lunch break and grilled me about my son's educational placement. When I told them Kevin attends a special school, the lecture began—I obviously

had *no clue* about the current thinking regarding education, and I was about to have a lesson. What I learned was astounding:

• I hadn't realized that all three-year-old children needed the inclusion of my son in their program in order to become fully-functioning, sensitive, caring adults. I thought I was responsible only to my son. I thought his needs were my first priority. Many times, I feel overwhelmed just providing for him; the needs of the entire three-year-old population of my community are more than I can handle.



• I didn't know my son wasn't meeting his full potential at that school. I thought a school that offers swimming, field trips, sing-alongs, sign language, parades, computers and the most up-to-date augmentative communication technology sounded fully prepared to bring out the best in my child. I thought that teaching my son to use a switch—despite his extreme physical and intellectual limitations—was a huge step in helping him reach his potential.

• I didn't know I was so unhappy having my son attend a special school. I thought I was comforted

. continued on page 56



Kevin Haney, 3, attends the Lincoln School in Ontario, California.



continued from page 55

by the fact that his teacher knew *exactly* how to suction and position and g-tube feed my kid. I thought I enjoyed the

feed my kid. I thought I enjoyed the monthly support group meetings led by the school's principal, on her own time. I thought I loved it that the staff was so taken with my son—that his teachers cuddle him and tell him jokes that make him laugh at the standing table.

• I didn't realize I didn't have a choice. Nobody had ever told me that choosing an appropriate educational environment for my son was not my choice. I thought all parents carefully weighed their choices and chose appropriately for their children. I did not realize I was sabotaging an

I was shocked. The "Inclusion People" were

entire educational movement by sending Kevin to

denouncing my choice—and an excellent one at that—sight unseen. I don't think it ever occurred to them that the population of people with disabilities is incredibly diverse, and that one program cannot possibly meet the needs of all. *Don't we still have room for choice?* 

Our family is happy with Kevin's school; we are happy with the way it is serving his needs and the needs of other children with very severe disabilities. I believe all children with special needs deserve a program that meets their needs—either full inclusion, a special school, or something in-between. And most of all, I believe all children deserve a chance at the happiness Kevin displays at his school.

—Jill Chester-Haney Ontario, California

# A Varsity Letter for Inclusion

M

a special school.

y son's graduation ceremony was a milestone for the whole family. As David marched across the stage, shook the principal's hand and then proceeded to envelope him in a giant hug, I felt an overwhelming rush of

joy—and a huge sigh of relief. David's educational journey required tremendous effort from

him and everyone else involved, but that effort reaped great rewards.

David, who has fragile X syndrome, began his education in a totally segregated setting; recess and lunch provided his only exposure to "regular" kids. The professionals seemed convinced this was the best place to maximize his learning potential. It wasn't until David was in fifth grade that a new special education teacher suggested we try a more inclusive learning environment.

I'll admit I was frightened! What if it didn't work out? Didn't David face enough challenges already? Would other children

David proudly wears his letterman's jacket everywhere he gc es — so, of course, he had to wear it for his senior picture!

tease him about his poor reading skills? And what about his hand flapping and hand biting? These behaviors often increased when he was in a stressful situation; how would the other kids react?

David was already the brunt of unkind comments and subtle abuses on the bus and playground. Very seldom did a day go by that another child did not greet him with, "Hey retard!" I wanted to protect him, to keep him safe. But I knew my husband and I would not always be there for David. If he was going to live independently after we were gone, he had to gain some of those important skills now. I · · · allowed my fears and agreed to try inclusion.

Initially, Dave was in the regular classroom only for a few periods each day, for subjects like art and gym. The following year, in sixth grade, he became a more active member of the class. He still ventured back to the resource room for reading and math, but the rest of his day was spent in the regular classroom.

It wasn't all smooth sailing. There were some initial problems, but slowly David began to change. His self-esteem increased. His behavior was not a problem. In fact, it was better in the regular class-room than in the self-contained setting.

And contrary to what many had predicted, David was learning. After years on the same level, his reading skills began increasing. He did well in social studies and science, showing great strength in general knowledge and awareness of current



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events, and often surprising teachers with his understanding of certain issues.

David's inclusion was not limited to the class-room. In seventh grade, he tried out for the school play and was given the part of a mummy in "Frankenstein Slept Here." On the night of the performance, my "shy, withdrawn, autistic-like" son slunk across the stage in a frightening mummy-like manner, remembered his four lines and showed us all what he could do when given the chance.

As a high school junior and senior, David was a member of the school's concert choir. He also served as football manager, receiving his varsity letter with the rest of the guys. He proudly wears his letterman's jacket everywhere he goes, even in the heat of summer. Participating in these activities increased his self-confidence, which carried over into other areas of his life.

As Susan McVicar, David's former special education teacher, says, "Every time David took a risk at school—whether it be talking with peers, presenting a report, handling the stress of the crowded hallways or participating in a school play—he was gaining life skills he could not

have gotten had he remained in a self-contained setting."

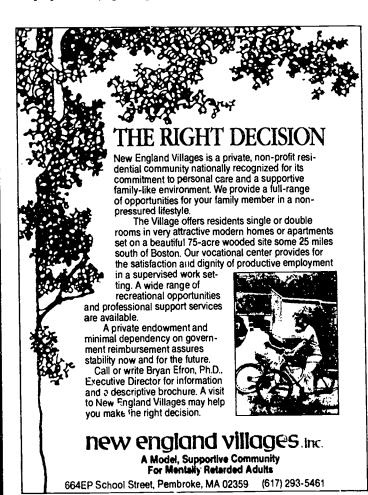
I know there is no single "right way" for all children; each child is unique. But my experience prompts me to encourage other parents to consider the benefits of some degree of inclusion for their own child. I don't believe we can expect individuals with developmental disabilities to suddenly, upon completion of their schooling, be able to function in a society they have been separated from for years. If we truly believe each person is of value and has the right to "belong" in the community, how can we support education that segregates?

We'll never know where David would be today had he remained in a self-contained class-room. But I believe the David who hugs me good-bye as he heads off to work each morning is a happier, more independent, more self-confident young man than he would otherwise be, and a strong testimony to the positive benefits of an inclusive education.

—Jeannie Lancaster Loveland, Colorado

More Readers Talk on page 58

IF WE TRULY
BELIEVE EACH
PERSON HAS
THE RIGHT
TO "BELONG"
IN THE
COMMUNITY,
HOW CAN
WE SUPPORT
EDUCATION
THAT
SEGREGATES?



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# **Amy's Experiment** with Inclusion



ow can you send your child to a centerbased school? She'll never learn how to behave unless she is around normal children!" I've heard this kind of accusatory statement from perfect strangers. I have no interest in arguing

about educational philosophy; I just want the best possible education for my daughter.

Amy, 8, was born with multiple disabilities due to congenital cytomegalovirus (CMV). She has a profound hearing loss, profound mental retardation, a visual impairment and mild cerebral palsy. She does not vocalize and has no language. She wears ankle-foot orthotics (AFOs), and began walking at four years of age.



Amy's "education" began in a home-based program when she was six months old. Teachers came to our home to provide speech, physical and occupational therapies for a total of six hours a week. At two, Amy boarded a school bus for the first time, entering a specialized preschool program at a local school. Three years later, she began kindergarten at a center-based school.

During those years, she made amazing progress. The little girl who would throw herself down on the floor in the grocery store was now able to walk nicely with Mom. She learned that pulling out her hearing aid and putting it in her mouth would result in a time-out. And most importantly, she was becoming potty-trained. She wore regular panties all day without an accident. She was beginning to form some signs and was learning to eat with a spoon.

Amy made so much progress, in fact, that her teachers began urging me to transfer her to a

self-contained classroom in a regular school. I visited the program they recommended and was quite impressed. Lessons were individualized, and children were able to spend some of their time in regular kindergarten or first-grade classes. With some hesitation I agreed to let Amy try this new school. The deciding factor was that she could continue to receive speech and hearing services from the same wonderful teacher she'd had in the center-based program.

The day before the 1994–95 school year was to start, I learned that this teacher had been transferred. To make matters worse, the experienced teacher I had observed during my visits the previous spring would not be teaching Amy's class; instead, her teacher was to be a recent college graduate with little experience.

I kept Amy home from school until I could meet with teachers and administrators from both schools. They all argued that Amy was "too smart" for the center school, that they would not be able to give her the stimulation she required, and that she would benefit from having "higherfunctioning" and "regular" kids as role models. I was finally persuaded; so began Amy's experiment with inclusion.

Amy immediately regressed in all areas. We began to realize that the physical differences in the new classroom were having a profound impact on her learning and independence. The bathroom was not situated so a child could be watched from the classroom, and no large potty chair was available; as a result, Amy did not use the toilet all year. Strapped into a posture chair, she spent hours staring at the bright florescent lights instead of watching the teacher. Her ability and willingness to use language-signing or pictures—disappeared. Her focusing skills deteriorated. And I noticed a growing frustration when it came to accepting direction. Amy, with a 14year-old brother and 11-year-old sister, was tired of being bossed around—both at home by her siblings and at school by her classmates!

We visited the center school again this spring. Many of the "higher-functioning" children have been moved to regular schools. None of the current students were as independently mobile as Amy, but some were at the same intellectual level. We think Amy would like to be a "big fish in a small pond" for a change—able to take the lead in group activities, able to push a friend's

wheelchair, able to be with children more like herself. Though we met with some resistance from school officials, we've decided that Amy will return to the center-based school in the fall.

Although Amy's experiment with inclusion was a failure, we strongly believe parents should have a choice of programs. Inclusion is truly beneficial for some children, and it is important to have the resources to allow a child to join a regular class when appropriate. But it is equally important for children like Amy to have other options that can better meet their needs.

--Margaret Daigle Falls Church, Virginia ME THINK
AMY WOULD
LIKE TO BE
A "BIG FISH
IN A SMALL
POND" FOR
A CHANGE.

# A Battle Well Worth Fighting

hree years ago, when my daughter was four years old, I had never heard the word "inclusion." But I did know Rachel used others as role models for speech and behavior, and it seemed only logical she would have more and better role models in a regular class.

Unfortunately, the "experts" in our school district believed in segregation. Rachel wasted her first year of school in a special day class for "speech-and-language-impaired" children. Her classmates had the same language difficulties as Rachel; some had behavior problems, too. All six were boys. Rachel spent that long year without another girl to play with; the only dolls in her classroom were the ones I donated. She didn't learn the language of play, because she never heard it.

At our next IEP meeting, the team was able to agree on most of Rachel's goals for the following year. But we reached an impasse when we started discussing the type of kindergarten class she should attend. Our school district dared us to file for due process; and we did. After several months of anguish, countless hours of discussion with our wonderful advocate and terrific attorney and more than eight hours of mediation, we finally had what we wanted—Rachel would attend the same school as her older brother, four blocks from our house. She would be fully included in a regular kindergarten class, with therapists coming into the class-room to work with her.

I wish I could say we all lived happily ever after, but that was not the case. We neglected to add one important item to our mediation agreement; we did not insist that the kindergarten teacher want the challenge of a child with disabilities.

Flachel (seated) celebrated her seventh birthday surrounded by friends from her first-grade class.

Unfortunately, Rachel ended up with a teacher who didn't want the extra work and didn't want to be part of a team. Because Rachel was labeled "special ed," the classroom teacher took no responsibility for her education.

Socially, however, kindergarten was the best thing that ever happened to Rachel. She learned what to say during play, and she had *lots* of other little girls to play with. Thirty friends attended her birthday party; she'd never had friends to invite to a previous birthday celebration.

Before the start of first grade, I spoke at length to the first-grade teachers I wanted Rachel to have. I explained that inclusion meant more work for them, but that they would also learn a great deal. They had never had a student like Rachel before—actually, she was the first fully-included child in the school—but they were happy to give it a try. I crossed my fingers and hoped for the best.

Like kindergarten, first grade was a terrific social experience. The kids volunteered to be Rachel's partners in group activities. They protect-

continued on page 60





continued from page 59

ed her, they included her, they played with her and they liked her.

Academically, the year was at least as good. Rachel was treated like every other kid. When the other kids took weekly spelling tests using pencil and paper, Rachel used her computer. She learned to read better than some of her classmates—an accomplishment acknowledged by teachers and kids alike. Math was harder, but her teachers spent extra time helping her and trying new instructional methods. The teachers did not give up, and as a result, Rachel didn't either. Everyone

in that classroom knew how hard Rachel worked. They respected her efforts and accomplishments and urged her to strive for higher goals. As a result, Rachel learned to do many things the "experts" said were impossible.

Dragging our school system into the 20th century has been a long, hard battle, but well worth the fight. I am reminded of that every time I look at my beautiful daughter's smile as she reads a story to her little brother.

—Margaret Simons Beverly Hills, California

# Never say "Never"

M

y daughter, Jamaica, was born totally blind due to anophthalmia, a condition in which the eyeballs fail to develop. From the time Jamaica was an infant, I was a believer in full integration. I was one of those parents who firmly states, "My

child will never go to a residential school." But now, I say, "Never say 'never!"



During a family vacation, the Millers—(clockwise from left) Jamaica, Tim, Lucky, Dixle and Diane—enjoy a fishing trip on the Gulf of Mexico.

Jamaica began her education in an integrated preschool and then attended the regular kindergarten class in our neighborhood school, receiving twice-a-week instruction from an itinerant vision specialist. On the other three days of the week, she had a personal aide in the classroom. Things went smoothly, and Jamaica developed many friendships with her classmates. But my husband and I still worried. Sighted children are exposed to print

every day as they develop early literacy skills. We thought Jamaica needed more intensive exposure if she was going to learn to read and write Braille.

We moved to another school district, where Jamaica could receive daily resource instruction from a vision specialist, and still be in a regular classroom with her sighted peers. We also asked that Jamaica receive orientation-and-mobility instruction. The school district was willing to provide these services, but unable to find a qualified instructor. Finally, they contracted with someone to provide once-a-month instruction. Jamaica needed more, but we figured a little was better than none at all.

All things considered, Jamaica's educational program was more comprehensive than those provided to most children with visual impairments in the public schools. But despite all the efforts on her behalf, Jamaica fell further behind each year. She was frustrated, and her teachers were frustrated. At this point, we began to look at the intensive, specialized programs that would be available to her in a residential school for students with visual impairments.

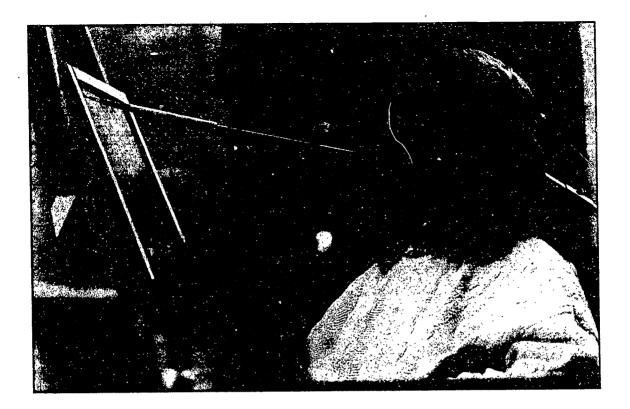
In spite of the fact that I had said "never," I was glad to have that option when we needed it. But I certainly struggled with the prospect of sending Jamaica away from home for an entire year. A wise counselor suggested a trial placement for the last six weeks of the school year. Jamaica did well, and we re-enrolled her for the following year. The intensive specialized instruction was good for her academically, but we couldn't muss the rest of her childhood; we moved again, so she could live at home while attending the school as a day student.

For a while, we thought we'd found the best of both worlds. But Jamaica's school was in a

EXCEPTIONAL PARENT

797

continued on page 63



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Spring Time by Amy Neubauer

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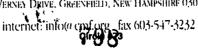
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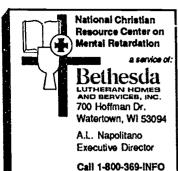








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Bethesda offers workshops and resources to help you build parish ministries which fully include persons with disabilities and their families. For more information call 1-800-369-INFO.

Circle #84

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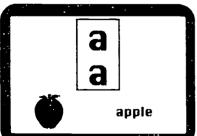
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Circle #265



Circle #16

continued from page 60

metropolitan area, and our home was in the suburbs. Jamaica had many friends at school, but few opportunities for integration into the local comnunity. It was still like she had a separate life from the rest of the family. Not every state has a residential school for the blind, and most schools are located in large cities. But we finally managed to locate a residential school in a small town—and we moved our family one last time.

Jamaica, now 17, lives at home and attends the school for the blind as a day student. Last year, she also spent part of each day integrated into a language arts class in the local high school, where she was with sighted friends she knew from church, gymnastics and Girl Scouts.

We believe Jamaica's well-balanced educational program is meeting her unique needs and preparing her for life in the real world. At the school for the blind, she gets daily instruction in orientation and mobility. She is learning to use new technology that enables her to communicate with people who do not read Braille. She is learning cooking and personal management skills to help her move toward a life of independence. Most of these opportunities

would not be available to her in a public school program.

On the other hand, her progress in the integrated language arts class surprised everyone. By October, she had already met her goals for the entire year! There is nothing equal to the motivation offered by friends.

Today, 17 years later, I still believe in full integration—integration of all the supports and resources necessary to meet each child's individual needs. I become very worrica when I hear talk of narrowing options and making services more generic. Instead, we need to broaden the educational opportunities available to children with disabilities and their families.

Has it been easy piecing together an appropriate educational program to meet Jamaica's changing needs? No! At different points along the way, we have used *every one* of the educational placement options available. Sometimes it seemed that our choices were very limited. But at least we had choices.

—Diane D. Miller Vinton, Iowa I STILL
BELIEVE
IN FULL
INTEGRATION
INTEGRATION
OF ALL THE
SUPPORTS
AND
RESOURCES
NECESSARY
TO MEET
EACH CHILD'S
INDIVIDUAL

NEEDS.

Vinton, Iowa More Readers Talk on page 64

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Circie #261





# "Real Inclusion" Starts With Us

t started simply enough as the 1991 school year began. Rather than busing our daughter, Sydney, who has Down syndrome, to the "special day class," we just opted to keep her in the local school. With that decision came a due

process hearing, in which we prevailed, and a far more complicated process known as "inclusion." It is an ongoing journey, not unlike that faced by those who fought for racial desegregation, 40 years ago.

Inclusion is not easy or simple. It is fraught with all the many challenges we had been warned about. At least once a week, I resolve to throw in the towel and as gracefully as possible, slink off to the nearest self-contained class with Sydney in tow.



Sydney (right) enjoyed her fourth-grade field trip to the San Diego Zoo.

In the past, following every inspiring conference or seminar, I would return to our school district full of enthusiasm and great ideas. It always seemed that "real inclusion" was happening just about every place but here.

But I now understand that the reality of inclusion can be found in the process that is happening in my daughter's class. Inclusion, we have learned, is a state of mind. It is not easy to change the "non-person" category into which so many individuals with intellectual challenges are placed. What keeps us going is the absolute knowledge that our daughter, and others like her, deserve the right to become valid and

valued members of the community. Meaningful inclusion must start here, and with us.

Still, it is hard not to get discouraged when Sydney plays alone at recess while her classmates giggle and laugh nearby. It sometimes takes my last bit of self control to field thoughtless comments—no matter how well intended—and the obvious lack of respect shown my daughter, unfortunately, all too often. It would be easier to escape from the assaults of the world, back into safer environments and settings. And who knows, perhaps someday we will.

But at discouraging moments, I try to reflect on Sydney's many accomplishments over these last three years. Now 12 and going into fifth grade. Sydney reads at her grade level, enjoys spelling and is mastering cursive writing. She takes piano and dance lessons, and has participated in her school's annual production of "The Nutcracker"—last year, as a candy flute.

Our goals for Sydney's inclusion are far more realistic now than they were at the beginning. Our family is facing the real world and trying to put together the many pieces that go into preparing any child for an independent and fruitful adult life. Inclusion doesn't mean insulation, and it doesn't mean automatic acceptance either. For that reason alone, perhaps inclusion isn't for everyone—but wouldn't it be nice if it were?

—Joyce A. Taylor Lake Forest, California

WHAT KEEPS US GOING IS
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AND VALUED MEMBERS OF THE
COMMUNITY. MEANINGFUL
INCLUSION MUST START HERE,
AND WITH US.

# Redefining "Least Restrictive Environment"

llow me to describe the "least restrictive environment" for my son, the placement every parent dreams of. It's a school where my child will learn on grade level, in a classroom of same-age peers, with a minimum of extra support services. Free

and easy communication will flow between my child, his peers and his teachers. Friendships will develop naturally—no one is receiving "extra-credit" to be my child's "buddy." He'll have the opportunity to earn? place on the honor roll without that damned asterisk after his name, to indicate "special educational programming." Of course, extracurricular activities will be wide open to my child! Join the basketball team? Sure, no need to include that on the IEP. Theater Club? No problem. Debate Team? Ditto. Student Council? Get out the felt-tip markers and start making campaign posters! Homecoming court, school dances, field trips, the prom-my child will have the opportunity to participate in any activity he chooses. No advance request necessary, no hurried meetings to adapt an IEP, no more frantic phone calls to the Statewide Family Advocacy Center for advice and support. My

child will have the opportunity to join the clique of his choice and the opportunity to go out on a date. I can't wait to experience the "normal" headaches that come with parenting teenagers.

"Nice fantasy," you say.
"Dream on!" you smirk.

No, really! Every word is true! And every opportunity described above has become my child's daily reality.

But would you believe me if I told you I refused this very placement for years? That's true, too. The very "normal" educational experience I just described is available for my son only at the state school for the deaf, a residential school located almost 200 miles away.

For too many years, I put all my child's eggs in the

"least restrictive environment basket"—in other words, our neighborhood school. As far as I was concerned, there was no option; he had to go to school here. Period. End of discussion. He had to learn to live in our "hearing world." We made academic plans that had to be modified and sometimes sacrificed. My son had limited friendships and no real social life.

ALL OF YOU WHO ADVOCATE FOR INTEGRATION AND

Then I began to meet adults who were deaf. I began to listen to their conversations, their stories, their experiences of learning to live in the "hearing world." Slowly, oh so very s-l-o-w-l-y, something began to nag at me. A light bulb went on in my head and steadily burned, becoming brighter and brighter. Finally I realized this: as much as we love our son, as much as we are willing to advocate for every right to which he is entitled, my husband and I are still hearing people. We could never teach our son how to live in a "hearing world." He

can learn that only
from the very people who have
done just that since the beginning of time—other people
who are deaf.

So please, I am asking all of you who advocate for integration and inclusion, please tread lightly. What might be right for your child will not be right for mine. Don't overlook the law's guarantee of a "continuum of placement options." You, too, may need that guarantee someday.

As for me—I gotta run. I need to get to the store before it closes. I have to buy a new outfit for the homecoming game. It's Parent's Day at my son's school, and I wouldn't miss it for the world!

—Susan K. Perrault Oneida, Wisconsin

Jacob Gillis, 16, shows off his favorite Christmas gift—a varsity jacket! Jacob, a member of the class of 1997 at the Wisconsin School for the Deaf, has competed for the school in football, basketball and track. Jacob was the foster son of Susan and Richard Perrault for more than eight years.







INCLUSION, PLEASE

**GUARANTEE OF A** 

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SOMEDAY.

TREAD LIGHTLY. DON'T

OVERLOOK THE LAW'S

**PLACEMENT OPTIONS."** 

You, too, may need

# A Report From the National School Bus Standards Conference

Ricon recommends ADA lift standards for specially-equipped school buses

nce every five years, school bus operators from across the country gather to update a document known as the "National Standards for School Bus Operations."

The 12th National Conference on School Transportation Standards, held May 21–25 1995 in Warrensburg, Missouri, marked the occasion of the most recent update to this document—including significant upgrading of the standards for specially-equipped vehicles used to transport students with disabilities.



Prior to the conference, several key equipment manufacturers, who served as advisors to the Standards Committee, presented recommendations on upgrading standards for various types of school bus equipment. Ricon Corporation, a leading lift manufacturer, presented a draft recommendation to upgrade equipment standards for specially-equipped buses used to transport students with disabilities. The Ricon recommendations were supported by other lift manufacturers, and were eventually accepted for adoption by conference delegates.

Although school buses are not required to comply with provisions of the Americans With Disabilities Act (ADA), the 281 delegates to the conference approved the Ricon proposal, a document that borrowed heavily from the ADA to describe standards for specially-equipped school buses. The Specially-Equipped School Bus Writing Committee used language similar to that used in the ADA to outline rules on passenger capacity, lift and ramp specifications, window glazing, aisle width, markings, securement systems and new technology.

Committee co-chair David Huff, a delegate from Montana, said the conference adopted "90 percent" of the ADA's requirements, but rejected as unnecessary an ADA requirement for door height sufficient to accommodate adults in wheelchairs. Consistent with ADA standards, however, the conference added the requirement for school buses to have a parking brake interlock, a mechanism that prevents lift operation if a vehicle's parking break is not engaged. This requirement will ensure that a school bus cannot roll while its lift is in use.

According to Dale Carpenter, vice president of sales for Ricon Corporation, "The difference between a lift that doesn't meet ADA requirements and one that does is about \$95." Carpenter added that the cost may go down as such modifications become standard within the industry.

#### Electronic communications systems

Illinois delegate Peter Grandolfo and delegates from other urban states argued for requiring an "electronic voice communications system"—meaning either a radio or a cellular phone—on each bus that transports students with disabilities. But delegates from mountainous and rural areas disagreed with that proposal. Utah delegate Ben Black, of the San Juan school district, was typical of the dissenters. "It's pretty obvious to me that a lot of these folks have never been out West," said Black. "I have 8,000 square miles of district to cover." Black went on to explain that his district includes places where neither radio nor cellular communications can be used.

Eventually, an amended version of the measure was passed. The new version excluded areas where electronic communication does not exist. In addition, the wording was changed to say that electronic communication "should" be required, rather than "shall be."

#### **Testing tie-downs**

The conference deleted an earlier version of its own testing standards to allow the Society of Automotive Engineers (SAE) to do even more stringent testing of wheelchair tie-downs. SAE tests will involve wheelchair-and-restraint/securement systems being smashed on a test sled at 30 m.p.h. Huff said the decision to go to SAE testing will "put teeth" in the standards adopted by the convention, "to see if these tie-downs are going to do what we want them to do."

#### Lift capacities

Members also voted to strengthen lift capacities hy adopting the Ricon-recommended "designload" standard of 600 pounds. In Solition delegates added a requirement that "the lifting mechanism and platform shall be able to lift a minimum of 800 pounds." This requirement should ensure that each bus has a lift with the capacity to safely and effectively lift even the heaviest power wheelchairs and their passengers.

#### **Belt cutters**

Finally, the conference required that a durable seat belt cutter should be kept in any bus that has wheelchair/mobility aids or "other assistive or restraint devices that utilize belts." The availability of the belt cutter means that in an emergency, a passenger can be quickly freed of the restraint system and evacuated from the bus.

#### Standardization leads to better service

The standards passed by this convention will be adopted automatically in four states and used as a guideline in most others. For companies like Ricon Corporation, the adoption of ADA standards for school-bus wheelchair lifts means a more standardized product, because these same lifts are already in use by paratransit systems that provide transportation to adults with disabilities. Because the same lifts will now be used in school buses, Ricon Corporation will be able to provide faster delivery times and better after-sale product support.

#### Ricon goes one step further

In assessing the impact of the new standards on student safety, Carpenter pointed out that the recent adoption of the ADA requirement for an inboard roll stop is a significant safety enhancement. The inboard roll stop is a 10- to 15-inch barrier that prevents a wheelchair from falling into the space between the edge of the lift and the side of the vehicle.

In addition, the new requirement for a supplemental restraint system means that all passengers using a bus equipped with a Ricon lift will be protected by a "safety zone" that includes an electrically-interlocked outboard passenger restraint belt. This exclusive feature—standard on all Ricon transit lifts—consists of a belt running across the outer side of the lift, above the outboard roll stop. This helps to protect passengers in wheelchairs from rolling off the non-vehicle side of the lift platform and falling to the ground.

Portions of this article were adapted with permission from SCHOOL TRANSPORTATION NEWS:



# A Great Scouting O

Troop #767SNS (Special Needs S)

County, CA, is just like any other box

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# **Guidelines for Using Transportation Services**

by Ned Einstein

ew things in life run as smoothly as they should-parents are particularly reminded of this truth on most weekday mornings, as they rush to get children ready for school and out the door. Likewise, special education transportation services may not always run as smoothly as we might wish. But parents can do many things to help.

Children and parents deserve safe, reliable transportation services that are responsive to their concerns. Parents

pay for transportation services either directly, through fees; or indirectly, through taxes. They have a right to expect these services to operate according to some standards of quality. Unfortunately, laws and regulations establish only minimum standards; and some states have no legally mandated standards at all.

Regulations, standards and contract requirements may affect the safety, reliability and responsiveness of transportation services. In general, service quality depends largely on the money available to pay for it. Within these limits, however, most of a transportation system's operating characteristics are within the control of the personnel in charge of running it. But an informed parent can make many contributions to safety and service quality.

#### **Understanding your** transportation system

To passengers and their parents, the "system" may seem to be simply the vehicle and its driver. But your child's



vehicle and driver are only one cog in a complicated system including layers of dispatchers, schedulers, telephone receptionists, mechanics, training instructors and managers. Vehicles must be purchased or leased, maintained. cleaned, fueled, inspected, licensed and insured, as well as scheduled and driven.

Under the best of circumstances, operating a fleet transporting hundreds of individuals with a variety of special needs, traveling in every direction at the same time, is a task of daunting complexity. Now imagine what happens when it rains... when new drivers are still learning their routes... when there are traffic delays and accidents... when passengers are not ready at their scheduled pick-up times... or when operating personnel are overwhelmed with telephone calls...

#### Parents can help

Parents can do much to help the transportation service run more smoothly. Here are a few guidelines:

• Be as flexible as possible in

accommodating schedules. Scheduling hundreds of students for pick-ups and drop-offs is difficult. Adjusting a driver's schedule to accommodate a simple request-for example. "Can't you come earlier?"-can destroy the logic of an entire route, force other pick-ups to occur out of order and increase ride times for other children on the route.

• Provide system officials with telephone numbers where you or others respon-

sible for your child may be contacted at all times. When a vehicle runs behind schedule, breaks down or experiences other problems, it can take hours to track down and notify each passenger's parents. Make sure operating personnel have the information needed to contact you quickly.

- Know your child's pick-up and drop-off times and the "window of flexibility" for each. For example, a 10-minute "window" for a pick-up scheduled to occur at 8:30 a.m. means the pick-up should occur between 8:20 and 8:40 a.m. Always try to have your child ready before the window of flexibility begins. When it rains or snows, have your child ready even earlier; a well-run system will automatically try to pick up its passengers earlier in bad weather. Do not telephone system personnel until the vehicle is genuinely late.
- Obtain telephone numbers of parents whose children are also on your child's routes. The most important numbers are those of passengers picked up and dropped off immediately



before and after your child in the morning and the afternoon. Conversing periodically with fellow parents can help you monitor the quality of service and identify problems. If you are worried about a late vehicle, call a parent whose child is picked up (in the morning) or dropped off (in the afternoon) before yours. Better yet, appoint one parent to be "route captain;" that parent can communicate with system operator, then communicate individually with other parents of children on the route.

- Establish a clear policy with system officials about "receiving" your child. It may not be safe for the driver to drop your child off without a responsible adult available to meet him or her. Let system officials know who is authorized to meet your child.
- Make arrangements for your child to be dropped off at another home on the route if you cannot be home to meet the vehicle. Let system officials know who this will be. If no responsible adult is at the drop-off point when the vehicle arrives, the driver may be required to keep the child on the bus. Drivers usually do not have time in their schedules to "swing back" mid-route to drop off a child. In a case like this, your child could ride for hours until the driver has an opportunity to bring him or her home.
- Always call system personnel to cancel pick-ups and drop-offs if your child will not be riding. Make these arrangements as far in advance as possible. When you want transportation service resumed, also remember to call system personnel in advance.
- Provide system officials with detailed information, in writing, about your child's physical and medical condition(s). Include notes about behavioral issues, and any other special concerns. Also include phone numbers of your child's doctors. Ideally, the system should collect this information in the same way for all passengers. If it doesn't, at least make sure it has this information for your child.
- Do not alter regular pick-up or drop-off locations. Organized and pro-

ductive transportation systems cannot juggle pick-up and drop-off points without inviting scheduling and dispatching chaos. If your child will be staying at someone else's home, make arrangements to have that person drive to the regular pick-up or drop-off point before the vehicle is scheduled to arrive, and wait for it there.

- Do not ask the driver to be a messenger. Call system officials to convey information, file complaints or ask questions. If a schedule change is necessary, don't discuss it with the driver; contact system officials directly. Don't ask the driver to transport notes, lunches or any non-health-related articles. Have your child do it.
- Communicate with system officials and personnel on all nonurgent matters during non-operating hours. Non-operating hours are those hours when children are in school. During operating hours, a system switchboard is often flooded with calls requiring immediate response from dispatchers and system managers. Unless there is an emergency or your child's vehicle is unusually late, do not contact system officials during operating hours.

# Understanding the system from the "operating perspective"

Share these ideas with the parents of other children on your child's route and others whose children use the same transportation system. You' child's transportation system will operate more smoothly if other parents also follow these guidelines.

Try to remember that the people operating the system do not see it the way you do. They can't. And they shouldn't. This does not mean your child is "just a number." But system officials are often responsible for the safe, reliable transportation of hundreds of children. And they have to exercise this responsibility within a

limited budget. While they try to accommodate most of their passengers' needs, they cannot possibly accommodate every need of every parent. When discussing problems with system officials, let them know you understand these realities. They will greatly appreciate your understanding, and in return you will receive better information about the system and help in solving problems. **EP** 

Ned Einstein is the president of Transportation Alternatives, a southern California-based consulting firm specializing in the design of school transportation systems for chil-



dren with special needs, and "paratransit" systems for adults with physical and developmental disabilities. A former consultant to the U.S. Department of Transportation, Mr. Einstein authored the summary report of the NATIONAL SURVEY OF THE TRANSPORTATION OF THE HANDICAPPED, a report to Congress that formed the basis of the transportation sections of the Americans with Disabilities Act (ADA). Mr. Einstein conducts workshops on special transportation services and regularly provides expert testimony and technical assistance to attorneys involved in transportationrelated cases, particularly those involving paratransit, school bus and special education services.

# What are your concerns about transportation services?

Do you think your child's ride is unreasonably long? Are you worried about safety issues? Do you wonder how your child's transportation provider chooses and screens drivers? Readers with transportation concerns may write to Ned Einstein, c/o EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146. Mr. Einstein will answer reader questions in upcoming issues of the magazine.

ERIC



Only after this sink has been adapted, can this young boy use it.

# Your Child's Bathroom

and Mike Gibbons built their new house, they had to think carefully about their son Anthony's bathroom. Anthony Rubino, 13, has quadriplegic cerebral palsy, and Jean and Mike were determined to create a home in which Anthony could have as much independence as possible. One

of the central features of that home turned out to be a ceiling-mounted lift that moves Anthony from his bed to the bathroom, and once there, from the toilet to the shower. The lift could be installed only because the Gibbons' architect made sure the configuration of the bathroom and bedroom was just right. Building a new home to meet the needs of a child with disabilities is clearly an ideal solution.

Unfortunately, not everyone can start from scratch.

When designing a bathroom for a child with disabilities—either as an adaptation to your existing home or as part of a new one—there are several goals to keep in mind. Independence and privacy are primary among them; it is important that a child be able to do as much as possible without someone else's help. This means considering details such as the height of light switches and the placement of towel racks. These details, in turn, highlight another priority—safety. Towel racks need to be within reach, but should also be positioned where they will not be confused with grab bars (see sidebar).

Children grow older, this fact often influences design decisions also. In a few years, for instance, your child's grab bars may be positioned too low to be useful. Planning ahead can help you avoid these problems. Grab bars, for example, will be

### Checklist for Your Child's Bathroom: Is it Convenient and Safe?

Remember that the bathroom must be big enough for your child and any adaptive equipment he or she needs, keeping in mind that both the child and the equipment will grow larger.

1. Personal Hygiene

- Is the sink at a good height for your child? Is it easy to adjust the height of the sink to accommodate your child as he or she grows?
- Is there a need for open space below the sink or vanity? If there is not a need now, will there be one in the future? If so, is it easy to remove cabinets to provide space?
- Can your child reach the faucet now? Do you anticipate further limitations in reach?
- Is the mirror at a good height for your child? Is it easy to adjust the height of the mirror? (Note: A large mirror meets the needs of everyone.)
- Is the toilet at a good height for your child? Is it easy to adjust the height of the toilet? (Note: Add-on seats are available.)
- Is the tub/shower easy to get into and use?
- Is there a tub/shower seat in the bathing area?
- Can the controls be reached from both a sitting and a standing position?
- Does the shower have a hand-held unit? Is it mounted so that your child can use it?
- Is the tub or shower floor a non-slip surface?

2. Support Systems

- Does your child need grab bars by the toilet? The height of the grab bars will need to change as your child grows; if the bars are mounted on solid blocking, is the blocking wide enough to allow the height of the bars to change substantially?
- Does your child need grab bars at the tub or shower? Is it easy to adjust their height? (See above.)
- If you have grab bars, are they sturdy? (Note: Towel cacks are often used as grab bars, but they were not designed to fulfill the same purpose and should be placed where they will not be confused with grab bars.)
- Even if your child does not need grab bars, will the caretaker?

#### 3. Accessories

- Is the toilet paper dispenser within reach?
- Are the towel racks at a good height for your child? Is it easy to adjust the height of the racks?
- Are the light switches easy to turn on and off?
- Are the electrical butlets appropriately placed? Do you need outlet covers?
- Are the electrical outlets grounded?

#### 4. Storage

- Is there adequate storage within reach? Storage needs may change; is extra space available if needed?
- Are the medicine cabinet and shelves within reach? Are they easy to open?
- Is there enough room for toileting/diapering supplies? Is there a surface for diapering?
- Is there enough room around the sink for the accessories your child will eventually need, for example, shaving items and make-up?
- Is there space to store a shower chair that can be used in a roll-in shower?

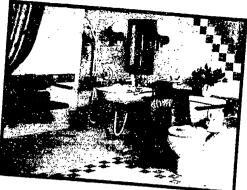
#### 5. Moving Around

- Is there space to move around in the bathroom in a wheelchair? Will there be sufficient space as your child and the wheelchair become larger?
- Is there room for both your child and a caretaker?
- Is the bathroom door wide enough? (Note: By widening it to 32" clear, it will meet your child's changing needs.)
- Is it easy to pull the door shut? Is it easy to open?

#### 6. Lighting & Ventilation

- Is there enough lighting in the bathroom?
- Is the bathroom well-ventilated?

Adapted from material in A CONSUMER'S GUIDE TO HOME ADAPTATION. \$12; available from Adaptive Environments Center, 347 Congress St., Ste. 301, Boston, MA 02210; (617) 695-1225.



Accessible bathrooms need not look institutional!

easier to raise if you place wide, solid blocking behind the walls so the bars can be re-mounted at any height.

Development may also bring changes in a child's abilities. If your

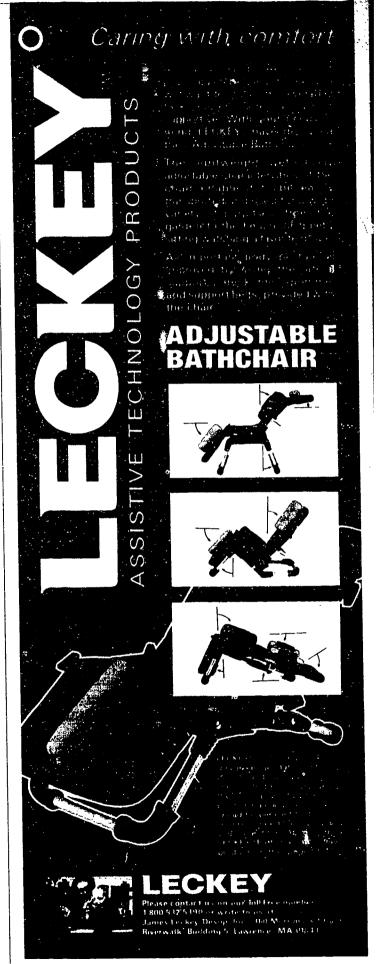
child may use a wheelchair in the future, for example, any under-sink cabinets need to be easily removable.

#### Resources

To begin gathering the necessary information to embark on an adaptation or design project, first get your child's occupational or physical therapist involved; that person can help you review needs and locate resources. Parents can search databases such as the ABLEDATA database of assistive technology (8455) Colesville Rd., Ste. 935, Silver Spring, MD, 20910-3319; 800/227-0216, V/TTY; 301/588-9284, V/TTY; BBS: 301/589-3563, 8-N-1, 1200-9600 baud). Other good places to find new products or services include:

- Adaptive medical equipment retail devler catalogs. Medical equipment dealers can show you their catalogs to give you design ideas and options.
- State assistive technology programs. To find these programs, which can direct you to resources in your state, contact the RESNA Technical Assistance Project, 1700 North Moore St., Ste. 1540, Arlington, VA 22209-1903, (703) 524-6686, voice; (703) 524-6630, TTY.
- Independent living centers. These community-based, consumer-controlled advocacy and service organizations can provide lists of resources for adaptation projects. To find the center nearest you, contact the National Council for Independent Living, 2111 Wilson Blvd., Ste. 405, Arlington, VA 22201, (703) 525-3406, V/TTY.
- · Specialized accessibility consultants. Make sure that any consultant you hire focuses on residential adaptations. These consultants, where available, help families target their specific design or adaptation needs. This process involves the whole family-it's important that a modification or adaptation for one family member doesn't interfere with the needs of another. After a discussion about needs, goals and options, the next step is research into resources and products. The consultant may serve as a liaison between the family, the contractor and the architect, to make sure all the necessary details are included.

Often, the ability to take advantage of design ideas, products and services relies on funding. Inexpensive solutions exist, but adaptation expenses inevitably add up. Finding funding requires legwork, and families have to be ready to live by the "bit here, bit there" principle. In order to finance the bed-totoilet-to-shower lift, Anthony Rubino's family looked everywhere for help with the \$10,000 bill. Eventually, the Knights of Columbus came through for them with a \$5,000 contribution and the Elks with \$100. As you investigate resources, be sure to ask for funding tips. Continued on page 72



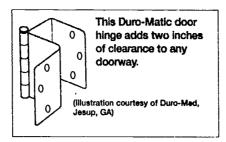
continued from page 71

#### A balancing act

In designing or adapting a bathroom, each decision is a link in a chain of decisions; one change can demand a whole series of changes. If you are building a new home, you have a great deal of flexibility—as

much as finances allow, you can aim for ideal solutions.

Modifying an already-existing house presents a different challenge; it forces you to find a balance between the ideal solution and the options dictated by circumstances. If you do not have room to replace an existing door with one that is three feet



wide, you have to find another solution. If the child's wheelchair does not need to make a *turn* to enter the bacaroom, the door can be narrower. Even if a turn is necessary, it may be possible to create the needed width with a pair of offset hinges.

These hinges have an extra fold, allowing the door to open further back and to the side so the inside edge of the door no longer diminishes the doorway's full clearance. This \$30 option may save a family up to \$600 in reconstruction costs.

The bathing area demands similar considerations. If your

bathroom already has a tub, you can install a lift—the most common type clamps onto the side of the tub. Or you could replace the tub with a shower, which may be easier to use. A pre-fab roll-in shower fits into the space of an existing tub. If the shower is not big enough for the caretaker as well as the child, a half-height curtain can allow the caretaker to work from outside the stall.

#### **Blueprints**

Talking about her work, accessibility consultant Jackie Dobson describes a moment she arrives at with many families-the .: oment when she says, "when your child moves to his or her own apartment..." Often, she can see that families haven't yet considered this eventuality-she watches them make a mental shift from the here-and-now to the future, and she can see their surprise. Jeff Jones, father of Brianne, a 14year-old with cerebral palsy, is thankful for moments like that. "Jackie personalizes it. You're busy thinking about 2x4s and she reminds you that girls need space to be girls-space for the hair dryers, you know?" Sometimes, a blueprint for a bathroom can turn out to be a blueprint for independence. EP

-Molly Winans

Molly Winans is assistant editor of EXCEPTIONAL PARENT.

Thanks to the following people for their contributions to this article:

- Jackie Dobson, president and founder of Solutions for Accessibility, Framingham, Massachusetts;
- Jean Gibbons, parent, Manomet, Massachusetts;
- Jeff Jones, parent, Cambridge, Massachusetts;
- Ralph LeBlanc, architect, Hull, Massachusetts.



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# O tva..ces

# **Genetic Counseling**

# ices in testing are changing the "typical pregnancy"

PART TWO

by Naomi Angoff Chedd

"CVS... AFP... DNA analysis... I thought I was going to have a typical pregnancy. Instead I was thrown into cauldron of alphabet soup!" This was the reaction of one mother upon learning that her genetic history predisposed her unborn child to a number of genetic conditions, including a major heart defect. Her pregnancy—which involved close monitoring, numerous tests and then, neonatal heart surgery—was anything but typical.

hese days, most pregnancies involve discussions of genetics, and many couples consult geneticists or genetic counselors. Some undergo a variety of tests in an effort to ensure that their developing baby is healthy, which, in most cases, it is. If not, prenatal testing can give families information and options.

But the accuracy of that information is crucial, stresses Suzanne Morse-Fortier, coordinator of the Down syndrome program at Harvard Community Health Plan and former board member of the Massachusetts Down Syndrome Congress. Morse-Fortier, who works with parents of children who have Down syndrome, or those who have received a prenatal diagnosis, believes that such parents receive too much negative and incomplete information because many medical professionals do not have up-to-date knowledge of various disabilities. For example, she points out, "People are often told that 30 to 40 percent of children with Down syndrome will have a heart defect, which is accurate. But they are not told that now, most of these heart problems are correctable."

Morse-Fortier thinks that couples with a prenatal diagnosis should find out as much as they can about the condition and available support groups and resources. They may also want to talk with other parents of children with a similar diagnosis.

On the other hand, Morse-Fortier adds, parents who have not yet decided whether to continue a pregnancy should not try to predict their child's future based on the way other children have turned out. "Do we parade expectant parents of what we believe will be typically-developing kids around youth detention centers, prisons—or Harvard University, for that matter—and tell them, 'Now pay close attention to this and think seriously about whether or not to continue your pregnancy, because your kid might end up here some day?' Of course we don't. Nobody can predict any child's future."

#### **Available tests**

About three or four in every 100 births results in some kind of genetic abnormality or "birth defect." Although tests are available only for a few hundred out of the thousands of possible conditions, medical knowledge and medical knowl-how are improving all the time. Here

are some tests that couples planning or expecting a baby may encounter:

#### Prenatal tests:

- Ultrasonography (ultrasound) is a non-invasive procedure that provides a visual image of the fetus. An ultrasound can be used to determine the size of the fetus and approximate due date. A more sophisticated level-II ultrasound can identify some developmental and structural abnormalities, such as spina bifida, congenital heart disease and hydrocephalus. Results are usually available immediately, although further tests may be reconumended to confirm a diagnosis.
- Maternal serum alpha-fetoprotein (AFP) analysis, a maternal blood test performed between weeks 16 and 18 of a pregnancy, indicates the level of AFP, a substance produced by the fetus and passed to the mother's blood. High

continued on page 76

### No cure... yet

wo-year-old Samantha Metcalf was born prematurely and diagnosed with cerebral palsy around her first birthday. Then, a few months later, Samantha's pediatrician noticed she had some "café au lait spots" (light, coffee-colored marks on the skin). Samantha was seen by a geneticist and at 18 months, diagnosed with neurofibromatosis (NF), a disease that causes tumors to grow along various nerves and sometimes in the bones and under the skin. The severity of NF varies widely-from almost unnoticeable to quite disfiguring. It can also lead to a number of medical complications including curvature of the spine, enlarged head, blindness and neurological problems.

"We got lots of information from our geneticist," explains Samantha's mother,

geneticist," explains Samantina's mother,
Emily. "At first the picture sounded bleak. But we found out that there's a
range of possibilities. The disease may amount to a few large spots on the
skin—which is most likely—or it may become more serious."

Samantha's NF is not related to her cerebral palsy or prematurity. It was caused either by a new mutation or by an altered gene inherited from one of her parents. NF is inherited as a dominant condition, meaning only one gene needs to be altered in order to have the disease. So if one parent has NF, each pregnancy has a 50 percent chance of producing a child with the disease.

DNA testing is now possible in most families with NF. The Metcalfs, who are awaiting the results of their DNA test, say, "We would go through toranstol testing if we decided to have a second child, although the test can't tell how severe the disease will be." Emily, who suspects she, too, may have a mild form of the disease, adds, "I'm optimistic about the future. When Samaritha was diagnosed nine months ago, there was no prenatal test for NF. Now there is Science is moving so fait, it gives the



Samantha Metcalf, 22 months, tries out the slide at a local playground with some help from her mom, Emily.



### New technology an option for some

During her first pregnancy, Renee Abshire, then 20, and her husband David, 24, never gave genetics a passing thought. But when their daughter, Maigon, stopped crawling and holding her bottle at seven months of age, they began to worry. Their pediatrician told them Maigon was "just getting a little lazy."

But as Maigon's condition worsened, Renee and David became increasingly concerned. The day Maigon had 39 seizures, the Abshires rushed her off to one of Louisiana's top medical centers, where doctors took a detailed genetic history and ran dozens of tests.

Since the Abshires are of Cajun decent—
Louisianians descended from French-speaking immigrants from Acadia, a region of eastern Canada—none of the specialists they consulted ever mentioned Tay-Sachs disease, which had always been thought to occur almost exclusively in Jews of eastern- and middle-European ancestry. But when a neurologist thought he saw the characteristic red spot in the center of Maigon's eye, he ran the test for Tay-Sachs and confirmed the fatal diagnosis.

Renee was alone when a doctor told her,
"Maigon has about three months to live."
Today, many years later, she still feels that,
"even with all the years of studying and experience doctors have, they just don't know how to
deliver bad news. They should take courses on
shis. It's as important as anything else they do."

After Meagon died atage three and a half, the Abshires didn't even think about having more children. "Nobody can put a child or thenselver through this a second time," says Renee, who started the Louisiana chapter of the National Tay Sachs and Allied Diseases Association. The Abshires know they bad a one-in-roor chance of the Sachs and allied places to the Sachs and Allied Diseases.

Marine - Marine & Marine

(Above) Proud father David Abehire holds newborn daughter Brittany Nicole for the first time. (Right) The new family sits for a portrait: Renee holds one-week-old Brittarry, while David holds a picture of the couple's first daughter, Meigon Nicole, Maigon, who is 32 months old in the photograph, died six months after it. was taken. "This is our only complete family picture," save

was available, Renee and David knew they would never terminate a pregnancy.

But five years later, they learned about a new reproductive technology—"pre-implantation diagnosis." In this modified version of in-vitro fertilization, the mother's egg is fertilized by the father's sperm in a petri dish in a laboratory and allowed to grow to the eight-

cell stage. Then a single cell is removed from the embryo and can be tested for a variety of diseases, including Tay-Sachs. If the embryo is disease-free, it is placed in the mother's uterus, with about a 20 percent chance of subsequent pregnancy and live birth.

Despite these low odds, the Abshires opted to try the new technique. Renee adds, "Even though the embryo might test negative for Tay-Sachs, we knew our baby could have another disorder. But we were willing to accept and love the child, no matter what?" bight ryonths after implantation, Rense gave birth to a daughter. Brittany, and the Abshires became the parents

of the first-ever baby born with the help of pre-implantation diagnosis for Tay-Sachs disease:

Now 18 months old, Brittany Abshire did need surgery after birth to treat a hip dislocation. "But," says Benez. "She's absolutely perfect to us. And each day she percent as a state of the surgery and percent to the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery and the surgery

continued from page 75

levels may indicate twins or that the due date has been miscalculated and the pregnancy is further along. But it may also indicate, among other things, that spina bifida is present or that the fetus has died. Because the maternal serum AFP analysis is only a screening test, amniocentesis and/or ultrasound are generally performed to clarify the cause of elevated AFP levels.

Low AFP levels may also warrant follow-up. Recently, doctors have discovered that women who have given birth to children with Down syndrome have very low AFP levels. So some clinics recommend anniocentesis and chromosome analysis if the AFP level is unusually low. At many clinics, testing for the levels of two hormones, estriol and human chorionic gonadotropin (HCG), has been added to the AFP analysis. Low AFP levels, combined with high HCG and low estriol levels, indicate a higher risk of Down syndrome.

• Amniocentesis, a widely-used procedure usually done between weeks 15 and 18 of a pregnancy, provides clear results 99 percent of the time. In this procedure, normally done on an outpatient basis, a small amount of amniotic fluid is obtained by passing a needle through the abdomen into the uterus. The cells in this fluid are analyzed for chromosomal disorders, and the fluid is analyzed for AFP levels. Additionally,

if the family has a history of a particular genetic disorder, amniotic samples can be tested biochemically or by DNA analysis.

Amniocentesis carries a slight risk of infection as well as a small increase in miscarriage rates. Many women report some pain connected to the procedure. Women older than 34, or couples who have already given birth to a child with a chromosomal or genetic disorder or have a family history of such a disorder, are generally offered this procedure. Results are available in two to three weeks.

• Chorionic villus sampling (CVS), done during the first trimester of pregnancy, allows doctors to diagnose many of the same conditions as amniocentesis, but earlier in the pregnancy. In this procedure, done on an outpatient basis, a sample of the placenta is obtained by passing a plastic tube through the vagina and into the uterus, or by passing a needle through the abdomen and into the uterus. CVS carries a higher risk of miscarriage than amniocentesis; also, some reports have suggested it is responsible for a rare limb defect.

#### **Newborn screening:**

Some type of newborn screening is mandated in most states. In most, babies are tested for metabolic disorders such as phenylketonuria (PKU), maple syrup urine disease,

813

Continued on page 78

Ter 2 160





# Berkshire Meadows

estled in the screne beauty of western Massachusetts'
Berkshire Hills, Berkshire Meadows' carefully designed fifteen-acre campus offers a comprehensive, integrated year-round residential program for children and adolescents who are severely developmentally delayed and may be multiply disabled.

ike other children all over the world, residents of Berkshire Meadows attend "school" (our Learning Center) five days a week. Each follows his or her own curriculum, designed to respond to individual needs: physical development, cognitive development (based on Piaget), the use of basic living skills. Our program for young adults also includes Applied Academics: techniques such as the use of money, and basic computing. And as a corollary to the Total Communication techniques we apply throughout our program, all students participate in Augmentative Communication training, where individual methods of communication are developed.





The young people live in spacious one-story homes, each with its own lounge, visiting area, kitchen, dining room, laundry and specially-equipped bathrooms. Each youngster has a bright, attractive bedroom, and is encouraged to keep personal pictures and toys. Here, in an atmosphere of nurturing home life, each resident learns about self-care and daily living skills, and staff accommodate personal needs with respect and tenderness.

E ach resident of Berkshire Meadows follows his or her own individualized physical therapy program. We take full advantage of all the tools and techniques that research and modern technology have provided to ease pain, relax muscles, develop strength and expand movement, including extensive hydrotherapy. Specialists in the fields of psychiatry and psychology work with the young people to promote emotional and mental well-being. Round-the-clock nursing coverage ensures that each child's physical needs are constantly and consistently monitored.

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ur intent is to help "our" young people to become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement and support. We believe that with thoughtful, cohesive integration of specialized education and physical care, and family and community support, each child has the opportunity to achieve his or her maximum potential, and, most importantly, to experience satisfaction and joy.

Berkshire Meadows
Gail Charpentier, Exec. Dir.
249 North Plain Road
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continued from page 76

homocystinuria and galactosemia. Some states also test for sickle cell disease, toxoplasmosis and endocrine disorder such as hypothyroidism and congenital adrenal hypoplasia. Screening for these disorders involves blood and/or urine analyses that can be done during the first few days of life. If a disorder is detected, treatment can be started immediately, and in some cases, physical or cognitive disabilities may be prevented.

Newborns can also be screened for hearing impairment using the brainstem auditory evoked response (BAER) test, which measures the brain's response to sound. Such testing is now mandated in several states.

#### If a problem is suspected:

Other tests that can be performed on newborns or older infants and children are not done routinely; rather, they are performed only if the child is suspected to have a specific condition. For example, children suspected of having a chromosomal abnormality such as Down syndrome, Turner syndrome, Klinefelter syndrome or others, can be diagnosed through chromosome analysis. This analysis can be done with a blood sample from the infant, which requires three to four days of cell growth in the lab, or with skin or other tissue samples, which require several weeks of cell growth. The analysis is done by examining stained cells

## Dealing with a lethal diagnosis

fter many years of infertility. Andrea and Peter Hart* became the proud and happy parents of a six-month-old adopted son. Then, unexpectedly, 39-year-old Andrea became pregnant. Her pregnancy progressed normally until week 20, when she went for what she thought would be a routine ultrasound.

But nothing turned out to be routine. Andrea and Peter's child was diagnosed with thanatophoric dysplasia, a growth disorder occurring once in about 10,000 pregnancies. The Harts consulted a genetic counselor to learn about the rare condition. Andrea explains, "We knew we could live with all kinds of disabilities, but these are the words that stuck in our minds: 'Your baby's condition is uniformly lethal.' So we made one of the most difficult decisions of our lives—to terminate the pregnancy." Throughout the emotionally and physically painful process, their genetic counselor was by their side, providing support and reassurance and helping them through their grief.

Afterwards, Andrea and Peter found a support group for people who have terminated a pregnancy after a prenatal diagnosis. "This is not the kind of thing people talk about openly or casually," says Andrea. "So you may never meet anybody else who has gone through a similar experience unless you join a group like this. It really helps to talk and listen to others." * Names have been changed.

under a microscope to look for extra, deleted, inverted or translocated chromosomes.

Screening for rarer types of metabolic disorders—such as the mucopolysaccharidoses or Tay-Sachs disease-is not done routinely at birth, but can be performed any time a problem is suspected. Testing for these enzyme deficiencies involves the

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# NO ONE TO PLAY WITH

THE SOCIAL SIDE OF LEARNING DISABILITIES Betty B. Osman with Henriette Blinder

ailing a spelling test is only one of a learning disabled child's many problems. Often having "no one to play with" can be more troubling and anxiety-producing than any classroom difficulty. This book offers parents and teachers compassionate insight into the special needs of a child with learning disabilities and gives detailed information about where to find support. 6x9 softcover, 170 pp. #687-8 \$10.00

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analysis of blood and/or urine samples.

An infant suspected of having cystic fibrosis may be given a sweat test, which measures the level of sodium chloride in a child's perspiration. A high level most often indicates that the disease is present.

Many other tests are available for diagnosing neurological disorders. These include various types of brain "scans" such as the electroencephalogram (EEG), which records the brain's electrical impulses; computerized axial tomography (CAT or CT scans) and magnetic resonance imaging (MRI), both of which can provide cross-sectional images of the brain's structures; and positron emission tomography (PET scans), which can be used to study the metabolic and chemical activity of the brain.

Most medical professionals would agree that the "typical pregnancy" is fast becoming a thing of the past. As a result, families are often faced with decisions for which they are unprepared. As more and more families face the difficult decisions created by progressively more sophisticated medical testing, the role of the genetic counselor may become increasingly important. One counselor put it this way: "If I can provide a greater level of comfort to people who need it, help them become better able to cope and give them enough accurate information to make decisions about their children or future children, then I am doing my job."

Naomi Angoff Chedd is a member of Exceptional Parent's editorial staff.

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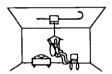


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# MEDIA

Irene Pollin, author of Taking Charge: Overcoming the Challenges of Long-Term Illness, is a parent and psychiatric social worker. In dealing with her children's illnesses, Pollin became aware that professionals receive scant training to help individuals and familias access with

viduals and families cope with longterm effects of chronic illness or disability. Neither mental health nor medical specialists provided the support she and her husband needed. After the loss of two of her own children, Pollin returned to school for training as a psychiatric social worker.

Although Taking Charge:

Overcoming the Challenges of
Long-Term Illness was written
specifically for individuals with
long-term illnesses, every chapter is
filled with powerful information and
helpful support for parents and other
family members. Taking Charge is
available from Except-ional Parent
Library (800/535-1910). The following is an excerpt:

# Mastering Your Fear of Expressing Anger

Anger is often difficult to recognize and acknowledge in oneself. You pay dearly when you cover your anger, trying to appear cool and controlled when you're not.

I know this from personal experience. I had no idea how much anger had affected my life—I didn't even know that I was angry. Some of my friends recognized it in me, but when one of my confidants mentioned that she thought I must be pretty enraged at what had happened to my family, I reacted as if she were crazy. "How dare she think I'm angry," I thought. "I'm upset and unhappy because of my children's deaths, but angry? Never."

Of course, I sometimes felt that



my life was over—I had put so much of it into my futile attempts at saving my sick youngsters. And certainly, I had asked myself repeatedly why two innocent children had to be born with such serious illnesses and had to suffer so. I wondered why all of my

friends seemed to be able to give birth to one healthy baby after another, while two of my three biological children were so terribly sick. I questioned if there was anything I had done to cause my children's pain, for I was certain that they had no responsibility in it. These concerns plagued me for years, yet I never recognized that I was angry...

WITHOUT WORKING
THROUGH MY ANGER,
I COULD NEVER RESOLVE MY
GRIEF. ONCE I FACED THESE
FEELINGS, I COULD REGAIN
CONTROL OF MY LIFE.

Indeed, I realized that sometimes I was impatient and short with my family... In addition, I felt deeply disappointed in close family and friends who seemed to misunderstand me. I used to ask myself. "Don't they know how terrible I feel? Can't they read me?" On many occasions, I sat in one room feeling as if my world had fallen apart, while my husband and surviving children laughed at a TV sitcom or cheered a sporting event in an adjoining room. If, in my state of upset, I came out to talk to them about my feelings, they gave me strange looks rather than sympathy or support. I needed their love and understanding, but felt, instead, isolated, insecure and "crazy..."

My family... must have felt that I

had changed. I knew I hadn't. Inside, I was still the same person, but I was hurting so much that I had no way to express it.

Moreover, my attempts at hiding my rage and pain made outsiders believe that I was cold and detached... In truth, I appeared calm because I was on tranquilizers... My doctor's idea, of course, was to get me through this difficult period, but in fact (as I realized later) the medication delayed my undergoing a process that was vital to my recovery.

Without working through my anger, I could never resolve my grief. Once I faced these feelings, I could regain control of my life...

# Use words to express your feelings

Anger can be understood, tolerated and discussed. For example, begin by explaining why it's so important for you to express your anger. Ask for indulgence and help. Tell your family that it feels awkward for you to be angry, but you know that you must be. You can even explain that you're not exactly sure why you feel this way, but you'd like their forbearance as you go through this difficult process.

You can also explain to your loved ones that all you want is an ear. You don't need them to solve your problems—they may be unable to, anyway. But their listening will give you a chance to release some of your pent-up feelings. It's something positive they can do for you.

In your discussion, simple expressions like "I feel so frustrated!" or "Sometimes I feel sorry for myself!" or "I'm just enraged!" help to break the ice without explosive outbursts that can be dangerous to you. You are describing how you feel without blanning anyone. And your loved ones will respond, but without an argument. They won't feel attacked or

need to defend themselves. After you have expressed your anger, its intensity will have diminished and you will regain a sense of control.

ANGER DUMPED
INDISCRIMINATELY MAY BRING
TEMPORARY RELIEF BUT CAN
PERMANENTLY DAMAGE
RELATIONSHIPS YOU REALLY
CARE ABOUT.

Be careful when you speak that you don't say things that can never be retracted or forgiven... Use "I" statements about your feelings (such as "I feel hurt when you don't call.") rather than "you" statements (such as "How dare you not call!"). Your friends and family will experience the latter as a form of verbal aggression and will become defensive. Anger dumped indiscriminately may bring temporary relief but can permanently damage relationships you really care about. "I" statements will garner a more positive response...

Finally, observe if your words and actions are in sync with your feelings. If you watch yourself, you may discover that you are one of those individuals (like me) who hide their true feelings. I learned that people often misread me because I continued to smile, even when I spoke of painful subjects. How could others know that I was hurting when my demeanor gave them a different message? While you may think that you are expressing how you feel, you may be conveying mixed messages. Make sure that those with whom you communicate fully understand you. **EP** 

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You can see the delight in Rebecca's eyes. When she answers a math question in her fifth-grade classroom...or creates art to hang in the halls of her school...or sings with the choir in a program at City Hall...she enjoys discovering her world.

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	Most all work in special education is focused on the child, his development status, his needs, his psychology, and the methodology required to educate him and develop in him the skills of inde-		☐ Giblin, Nan J. & Barbara A. Bales — FINDING HELP: A Reference Guide for Personal Concerns. '95, 224 pp. (7 × 10), \$49.95, cloth, \$29.95, paper.
	pendent living to the greatest degree possible. While the emphasis on the child is certainly required, in all the effort expended, parents have received very little attention. What happens to parents when their child is born with a severe	(	☐ Wodarski, Lois A. & John S. Wodarski.—ADOLES-CENT SEXUALITY: A Comprehensive Peer/Parent Curriculum. '95, 168 pp. (7 × 10), 3 il., \$43.95, cloth, \$29.95, paper.
	handicap? What is the effect upon the marriage? How do parents deal with the emotional, social, and financial problems presented? How do they find services? What happens when services are far away or not even available? How does a severe		☐ Sprandel, Hazel Z.—THE PSYCHOEDUCATIONAL USE AND INTERPRETATION OF THE WECHSLER ADULT INTELLIGENCE SCALE—REVISED. (2nd Ed.) '95, 238 pp. (7 × 10), \$73.95, cloth, \$33.95, paper.
	handicap change parents and their attitudes to- ward their own child, toward the medical pro- fession, and toward governmental authorities? This book attempts to answer these questions through the voices of parents themselves to give the reader.	!	☐ Camerer, M. C.—A PARENT'S GÜIDE TO COPING WITH ADOLESCENT FRIENDSHIPS: The Three Musketeer Phenomenon. '94, 174 pp. (7 × 10), 1 il., \$29.95, cloth, \$15.95, paper.
	a better understanding of the coping process. Parents from differing backgrounds and cultures present their personal accounts of how they dealt with their handicapped child from birth through adulthood. After each story there is an interpre-		☐ Anderson, Frances E.—ART-CENTERED EDUCA- TION AND THERAPY FOR CHILDREN WITH DIS- ABILITIES. '94, 284 pp. (6¾ × 9¾), 100 il., 14 tables, \$44.95. \$29.95, paper.
	tation and commentary by an authority in the field of special education. The distinctive nature of this book is not to draw particular conclusions but to give the reader a view into the lives of a group		☐ Fadely, Jack L. & Virginia N. Hosler—ATTENTIONAL DEFICIT DISORDER IN CHILDREN AND ADOLES-CENTS. '92, 292 pp. (7 × 10), \$51.95. \$30.95, paper.
	of parents who have had to deal with some of the most difficult problems a parent can face and how they found the inner resources to cope.		☐ Anderson, Frances E.—ART FOR ALL THE CHIL- DREN: Approaches to Art Therapy for Children with Disabilities, 2nd Ed. '92, 398 pp. (6¾ × 9¾). 113 il., 19 tables, \$61.95. \$39.95, paper.
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# ASK.THE DOCTOR.

by David Hirsch, M.D.

# "Burping" Through G-Button

My daughter had a Nissen fundoplication at the age of nine months and had a gastrostomy tube (g-tube) placed at the same time. The swallowing disorder that necessitated the g-tube (a button has since been placed) was felt to be caused by complications of a craniofacial condition. This condition was corrected by surgery and by her own growth. She is now five years old and is able to eat and drink well. We do not use the gastrostomy to feed her anymore and would like to have it removed.

Our problem is that the Nissen worked too well, and she is unable to burp. Our daughter's surgeon feels that the opening between her esophagus and stomach is normal for her age and doesn't think anything else can be done. But because she cannot release air through this passage, she often becomes uncomfortable during meals and asks us to vent the air in her stomach through her gastrostomy button. We are afraid to remove her button at this time because she needs it to burp, but we would like to remove it because she does not need it to eat. Will she need to keep it forever?

In this volumn,
David Hirsch, M.D.,
a podiatrician and
member of the
Excertioned Advisory
Board, answers questions from couders.
Dr. Hirsch is a partmer in Phoenix

Pediatrics, Ltd. in Phoenis, Arizona. He specializes in treating children with developmental disabilities and chronic illusieses.

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mentions of specific products or medications illustrates suggestions, he is not endorsing any specific products.

Send questions to Lak the Doctor, Exceptional PARSNT, 200 Harvard Street, Suite 303, Brookline, MA 02146-5005, (\$17) 730 8748 (Box) Your daughter has a problem we typically do not see. In fact, many children with fundoplications (a surgical procedure where the opening between the lower end of the esophagus and the top part of the stomach is narrowed to prevent stomach contents from flowing backward into the esophagus), who are not yet oral feeders, often need to have the fundoplications re-done after five to seven years.

Your daughter may need intermittent dilatation of the valve between her esophagus and stomach—a procedure in which the sugeon enlarges that opening by stretching it—even though it appears to be "normal" in size. Also, medications to relax the sphincter (valve) between her esophagus and stomach may be helpful. Again, however, this is not commonly done.

Have you tried using some of the common "gas" medications such as simethicone? This medication may help to break down some of the large air bubbles in your daughters stomach into smaller ones that are easier to pass. Some of the newer medications that increase gastric and intestinal motility (the ability of the gastrointestinal tract to propel digested food through quickly) may also be useful.

As your daughter gets older and bigger she will probably "outgrow" this problem. But until you see some improvement in her condition—as a result of trying some of these suggestions or because of the passing of time-I believe you should leave the button in place, as long as no further complications occur. But ask your daughter's surgeon about the possibility of replacing the existing gastrostomy button with a smaller one. That will allow for quicker closure of the opening in her stomach when you are finally able to remove it. **EP** 

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Circle #184

# **Issues and Answers**

**Books and Videos About Living With Seizures** 

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Comprehensive guide to help parents of very young children with epilepsy understand and manage their child's seizure disorder.

Answers common questions about epilepsy (seizure types, medical testing and treatment) and addresses family relationships, parenting skills and child development. Information about resources and questions about child care are discussed. (1993)

Catalog # 205GPB 105-Page Guide \$11.66 EFA Member \$12.95 Non-Member

Issues and Answers: A Guide for Parents of Children with Seizures, Ages Six to Twelve

Comprehensive guide to help parents of children ages 6-12 understand and manage their child's seizure disorder.

Answers common questions about epilepsy (seizure types, medical testing and treatment) and addresses parenting skills and developmental stages of this age group. Discusses how to help your child succeed in school and addresses afterschool care concerns. Includes list of resources for parents. (1993)

Catalog # 206GPS 102-Page Guide \$11.66 EFA Member \$12.95 Non-Member Issues and Answers: Exploring Your Possibilities: A Guide for Teens and Young Adults with Epilepsy

Comprehensive guide to help teens and young adults with epilepsy lead a full and healthy life. Answers common questions about epilepsy (seizure types. diagnosis. testing and treatment). Addresses common myths. misconceptions. and concerns of teens and young adults (medication side-effects. drinking. drugs. participation in sports. driving and having children). It also reviews many other areas of concern (school. behavior. friends. social pressure. independence. college and work). (1992)

Catalog # 165ITA 73-Page Guide

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Issues and Answers: A Guide for Parents of Teens and Young Adults with Epilepsy

This guide will help parents understand the special concerns of their teen with epilepsy. Provides general information about seizure disorders (causes, testing, and medication), and focuses on helping young people with epilepsy develop a positive attitude. Information about social issues (dating, driving, drinking, drugs and marriage) are addressed and practical suggestions for helping young people with epilepsy adjust to and cope with the disorder are also included. (1992)

Catalog # 164IAP 110-Page Guide \$11.66 EFA Member \$12.95 Non-Member

# The Teacher's Role, A Guide for School Personnel

Tips on recognizing scizures and handling a scizure in the class-room are reviewed. Additionally, provides guidance on how to help other children understand epilepsy and how

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# HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

# The Usual and Customary Rate

My son is a bright five-year-old with spastic quadriplegic cerebral palsy. He has had a manual wheelchair since he was two.

It is very tiring for my son to move himself from one location to another, so usually we push him. I have been considering a power wheelchair to give him more independence.

He's now covered under a comprehensive major medical plan. I know they provide coverage for durable medical equipment, and I know what to do to convince the insurance company of the medical necessity of a power wheelchair.

My concern is the insurance company's use of the phrase "usual and customary amount." A power wheelchair is expensive, and the amount the insurance policy will pay may be much lower than its actual cost.

What recourse do I have if my insurance company determines that our claim is greater than the "usual

and customary amount?" How would I handle a scenario in which I find an appropriate wheelchair for \$23,000, and the insurance company determines that \$12,000 is the "usual and customary amount?"

A Disagreements between consumers and insurance companies often center around the issue of "usual and customary amount"—or "usual and customary rate" (UCR), as it's technically called. The insurance company calculates the UCR by analyzing the charges for a medical procedure or piece of equipment from a number of medical providers in the same geographic area.

It's important to remember that insurance policies sometimes set payments to a specific "percentile" of the UCR, rather than to the full UCR. Percentile is a complicated statistical concept. In this case, a percentile generally refers to the level at which a

specific percentage of charges fall. For instance, if a charge falls at the 80th percentile, 20 percent of medical professionals charge more than that amount, and 80 percent charge less.

Let's say that a consumer has filed a claim for \$150 for a medical procedure. If the UCR is \$130, and the policy provides for payment at the 100th percentile of the UCR, \$130 is the maximum amount the insurance company will consider paying, even though the original claim was for \$150. However, if the policy provides for payment at a lower percentile of the UCR-the 80th percentile, for instance-and if the 80th percentile of the UCR is \$115 for that procedure, then \$115 becomes the maximum amount the company will consider.

Given the practice of set-

ting payments to specific percentiles of the UCR and given the high cost of power wheelchairs, your concerns are valid. Fortunately, there are several steps you can take to avoid a situation in which you purchase a power wheelchair and then find the insurance company will reimburse you only for a small percentage of the bill.

First, work with your child's doctor and physical therapist to determine the specific power wheelchair and accessories your son requires. Then ask both doctor and therapist to write letters to the insurance company listing those items in detail.

Second, before you purchase the wheelchair, ask the doctor to file a "pre-determination of benefits" request with the insurance company. (A copy of the letters from the doctor and physical therapist should be included with that request.) Insurance companies generally respond to a request for a pre-determination of benefits within a few weeks. That response usually includes a summary of the claim and an estimate of the amount the insurance company will consider paying when the claim is approved. You can then decide whether to purchase the wheelchair or-if the insurance conpany's estimate appears too lowwhether to file an appeal.

Some insurance companies have specific requirements for the purchase of expensive medical equipment. If you decide to purchase the wheelchair, make sure you follow those requirements in detail.

The Arc Plan and the COBRA Law

Recently, I've received a number of letters from readers asking about the availability of health insurance for children with disabilities. Several letters ask specifically for information about The Arc's new major medical plan; others just request information about any health insurance plan that might consider insuring a child with a disability.

In some cases, The Arc's new health insurance plan may provide a solution. The Arc plan, however, is only available to Arc members and members of their families, ages 10 to 65. In addition, while the plan does not automatically exclude children with disabilities, there is no guarantee of acceptance; each applicant's medical history and insurability is evaluated individually. For information about The Arc Group Major Medical Insurance Plan, contact the Albert H. Wohlers Company, 1440 N. North West Hwy., Park Ridge, IL 60068-1400; (800) 323-2106.

If a child is not accepted for coverage under The Arc plan or if the child is too young to be considered for coverage, extending an existing insurance policy through COBRA may provide a temporary solution. The COBRA law requires an employer to continue health insurance coverage for a set period of time when employment ends or other disqualifying events occur. (Call COBRA at 202/219-8784 for more information.)

Since the most important aspects of the debate on health care reform seem to have shifted to the state level, it's essential that readers write to state legislators with their concerns about health insurance coverage.

In this column, Richard Epstein

answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.



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# WHAT'S HAPPENING



Gianna, a VACC camper from Minnesota, enjoys the Florida sunshine on Miami's famous South Beach.

#### VACC Camp 1996

Plan ahead! VACC Camp '96, a free camp for children needing oxygen, tracheostomies, ventilators, BiPAP or CPAP—and their moms, dads and siblings—will be held in Miami, Florida, April 9–15, 1996. VACC Camp gives families a fun opportunity to

socialize with peers and enjoy activities not generally accessible to children who are technology-dependent. Activities include field trips, swimming, games, arts & crafts, entertainment and special events. The application deadline is January 5, 1996. For more information, contact coordinator Cathy Klein, Ventilation Assisted Children's Center (VACC), Div. of Pulmonology, Miami Children's

Hospital, 3200 SW 60th Ct., Ste. 203, Miami, FL 33155-4076; (305) 662-8222; (305) 663-8417, fax.

Morgan, a VACC camper from Florida, plugs his tracheostomy with a cap and takes a plunge in the pool with his mom.



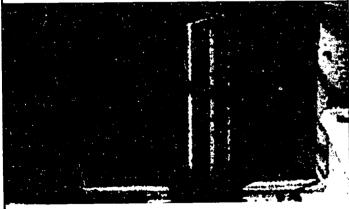
#### **Publications**

- A new edition of Fanconi Anemia: A Handbook for Families & Their Physicians is now available. Fanconi anemia (FA) is a hereditary form of aplastic anemia, associated with cardiac, renal and skeletal abnormalities. Updated sections of the handbook cover bone marrow transplants, gene therapy and long-term clinical treatment. The book costs \$2.50, including postage, in the U.S.; \$5 elsewhere. FA Research Fund, 1902 Jefferson St., Ste. 2, Eugene, OR 97405: (503) 687-4658.
- The Parent's Guide to Drug Treatment of Fragile X Syndrome is a 100-page, detailed guide to medications commonly prescribed to help manage symptoms of fragile X syndrome. A reference page includes a rating for each drug's effectiveness, safety, convenience and cost. The book costs \$25; all proceeds benefit fragile X research. FRAXA, P.O. Box 935, West Newbury, MA 01985-0935; (508) 462-1990; e-mail: fraxa@destek.net.
- Facing Neurofibromatosis: A Guide for Teens is a free booklet that answers common questions teens with neurofibromatosis (NF) may have about their condition. Send \$1 (to cover postage) to the National Neurofibromatosis Foundation (NNFF), 95 Pine St., 16th Fl., New York, NY 10005. For more information about NF, call NNFF at (800) 323-7938, voice/TTY; or while traveling the Internet, visit the NNFF home page on the World Wide Web at http://nf.org/.

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Circle #48





# NEW PRODUCTS



# **TOOBERS & ZOTS**

Toobers & Zots is a large-scale construction toy for children older than three. Using large tubes and shapes of

soft foam, children can create animals, flowers, cars, crowns—almost anything their imaginations can conceive. Toobers are brightly colored foam tubes, designed on the concept of giant pipe cleaners, ranging in length from two to four feet. Zots are an assortment of stars, circles, squares, triangles and other shapes, which fit onto the toobers. The large-scale pieces encourage creative play for children with physical and visual disabilities. Toobers & Zots are available in 20-, 50-, 120- and 180-piece sets, each with bilingual English/Spanish instructions and a mesh storage bag. **HandsOnToys**, Woburn, MA 01801

Circle # 195

# **WALKABOUT III**

The Walkabout III is a mobile stander designed for use by adolescents. As the child steps forward, the stander provides spring-assisted lift and allows forward motion. The



unit also provides lateral support to provide additional stability. It has an adjustable-width frame to accommodate growth. The unit can be positioned in front of a table and locked in place.

Available options include handholds with forearm supports, no back-up brakes and shoulder pad supports.

**Mulholland Positioning Systems, Santa** Paula, CA 93061

Circle # 196

# **PANDA**

The Panda is a pediatric stroller and postural positioning system available in 10 models and three sizes—mini, midi and large. All models feature a lightweight, folding, aluminum-frame mobility base and a positioning insert



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Taylor Made Health Care, Gloversville, NY 12078 Circle # 197

# STICKY BEAR'S EARLY LEARNING ACTIVITIES

Sticky Bear's Early Learning Activities is a software program designed to provide basic skills practice for children aged two to six. The program includes activities in six areas: alphabet, numbers, categories, shapes, opposites and colors. Each activity features animated graphics and



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activities are bilingual—English/Spanish. The program is available for both IBM-compatible (requires Windows) and MacIntosh computers.

Optimum Resource, Inc., Hilton Head, SC 29926 Circle # 198

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Circle # 199

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Taylor Made Health Care, Gloversville, NY 12078

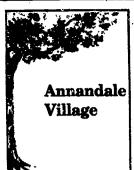
Circle # 200

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on Exceptional Parent's "Free Product & Information Card." Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).



829



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John P. Stewart, M.D., Resident Physician

Circle #4

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Announces a new deluxe care group home in Kendall, Florida.

We offer: private room • gourmet meals • extra staff to go with our nationally-recognized training and recreational programs for the developmentally disabled

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Haven Center is a non-profit, fully accredited residential and developmental facility



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National Christian Resource Center on Mental Retardation Bethesda Lutheran Home & Service

700 Hoffman Drive Watertown, WI 53094 (800) 369-INFO See ad on page 62

# Connecticut

CIB / Oak Hill School

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Oak Hill School has been meeting the needs of children with multiple disabilities for over 100 years and believes that each student, regardless of the severity of his/her disability, can make progress. Our residential education programs are community-based and provide an environment that is both supportive and challenging. See ad on page 93

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Threshold, inc.

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# Georgia

**Agape Village** 

3711 Agape Village Rd. Macon, GA 31210 (912) 471-3700 Providing mentally disabled with 50 acre protected place to live. work in greenhouses and enjoy active life with supervision. See ad on page 63

Annandale Village

3500 Annandale Lane Suwanee, GA 30174 (770) 945-8381 Private, nonprofit community for adults with developmental disabilities. Full residential, day, and evening programs and services promote well-balanced lifestyles which include a broad range of activities. Located on 125 wooded acres near Atlanta. See ad on page 93

### Kansas

**Heartspring** 

2400 Jardine Drive Wichita, KS 67219-4699 (316) 262-8271 Heartspring serves students ages five through 21 who have multiple disabilities and communication disorders. We serve residential school and day-only students. Outpatient assessments. short-term treatment programs, and hearing center services are also offered.

See ad on page 81

# Kentucky

The Stewart Home School

Box 20 Frankfort KY 40601 (502) 875-4664 Progressive education, home environment for mentally handicapped children and adults. Multiple recreation and activities. Year round program. Est. 1893. Call or write for brochure. See ad on page 93

# Maine

Bancroft

Lighthouse Road Owl's Head, ME 04854 (207) 594-7261 Year-round programs and vacation options for people with developmental disabilities/head injury. See Bancroft in New Jersey section.

# Massachusetts

Berkshira Meadows

249 N. Plain Road Housatonic, MA 01236 (413) 528-2523 For children and adults who have severe neurodevelopmental disabilities and complex medical problems. Private, non-profit residential setting in the Berkshires, offering a comprehensive approach to each individual's well-being with integrated educational, medical and rehabilitative services.

See ad on page 77

Crystal Springs School

38 Narrows Rd. Box 372 Assonet, MA 02702 (508) 644-3101, Ext. 328 Established in 1953, Crystal Springs offers licensed home-like residences; and approved private school; full rehab, program; and 24-hour licensed nursing coverage designed to meet the needs of medically fragile, multi-handicapped children and young adults, birth-22 yrs. See ad on page 78

**Cotting School** 

453 Concord Avenue Lexington, MA 02173 (617) 862-7323 Cotting School welcomes boys & girls ages 3-22 with physical, medical, learning & communication disabilities. We offer individualized academic, pre-vocational and social experiences to build confidence & enhance students' self esteem.

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Latham School: R.R.C.I.

P.O. Box 1879 1646 Main Street Brewster, MA 02631 (508) 896-5755 Special education / residential school for girls ages 8-22 with mild dev. delays and ED/BD Contact: Shirley Landers-Pfautz

League School of Boston

225 Nevada Street Newtonville, MA 02160 (617) 964-3260 See ad on page 22

The Learning Center

411 Waverley Oaks Road Waltham, MA 02154 (617) 893-6000 Children and young adults with MR, autism, communication disorders, challenging behaviors, developmental disabilities, 12 mo. day/residential.

See ad on page 93

The New England Center for Autism

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Riverview School

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St Coletta's of Massachusetts Cardinal Cushing School and **Training Center** 

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See ad on page 91

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See ad on page 24

**Woods Services** 

RT. 213, Langhome, PA (215) 750-4231 Woods services, founded as the Woods School in 1913 provides specialized residential, educational and therapeutic services to children, adolescents and adults with developmental disabilities, emotional disorders, physical and sensoral handicaps and challenging behaviors.

See ad on page 93

Rhode Island

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Providence, RI 02906 (401) 274-6310

See ad on page 62

To place an ad, contact:

**ROY WHITAKER** 

(505) 821-3414 or fax to:

(505) 821-2178

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See ad on page 95

### Wisconsin

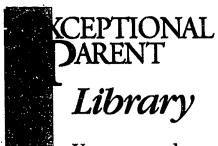
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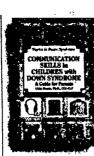
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# CHILDREN'S PAGE

# The Special Visit

by Kristina Ferrini

ast year, my fifth-grade teacher, Mrs. Jenkins, had our class read a book called *Welcome Home, Jellybean*, by Marlene Fanta Shyer. The book is about a dad and mom who put Gerri, their daughter with mental retardation, in a training school. Eventually, they are able to bring Gerri home for good, but they know things will be different now.



Like most 14-year-olds, Joev just loves pizza!

In the book, Neil, Gerri's younger brother, tells about how the family never gets enough rest because Gerri bangs her head on the wall at night. Gerri sits on to of the piano, and her dad always gets mad about that. Every time someone comes into the house, Gerri runs up and hugs the per-

son. The mom is always busy. The dad leaves, because Gerri gets to be too much for him. Neil decides

to live with his dad, but then he comes back home.

Since Gerri, the character in the book, has disabilities, I thought of my 13-year-old brother, Joey, because he has disabilities, too. I told my mom about the book. I brought the book home and my mom read it. Together, Mrs. Jenkins, my mom and I decided to have my brother visit my class.

The day before Joey's visit, my mom came into my classroom to answer questions from the kids. They asked a lot of questions: How did you find out Joey had disabilities? What is his favorite sport? Does he ride a bike? What are his strengths and weaknesses?

The next day, when Joey came to my class, he seemed nervous. I was nervous, too, but I did

To order *Welcome Home, Jellybean,* send a check or money order for \$3.95 plus your state's



sales tax to Simon & Schuster, 200 Old Tappan Rd., Old Tappan, NJ 07675-7095. Include the book's ISBN number: 0-689-71213-8. This book is also available from Exceptional Parent Library (800/5.35-1910). Order number: \$\$126OD



Two of Kristina's classmates meet her brother, Joey (right).

well. Joey read to the class and showed how he could do addition. Then some kids helped him color. The class enjoyed Joey's visit. **EP** 

Kristina Elizabeth Ferrini, 11, is a sixth-grader at Zellers Elementary School in Strongsville, Ohio. She enjoys violin and piano lessens. Her other hobbies include crafts and gymnastics. Joey, now 14, has cerebral palsy, mental retardation, epilepsy and asthma. Joey attends a special education program at Albion Junior High School, also in Strongsville.



# Mom's turn:

Kristina told me she thought I might enjoy reading Welcome Home, Jellybean because it was about a girl named Geraldine, who was a lot like our Joey. Kristina was right. The author painted a vivid picture of life with a child who has a disability. A few times, I found myself reaching for a tissue because the challenges and frustrations faced by the family in the book seemed as real as they can be in our own family.

Life with a child like Joey takes a lot of love, time, patience and understanding. We often realize that other families do not always see things from the same perspective. We hope to show everyone that we love Joey and are committed to helping him in any way that we can. Our family is a team.

I enjoyed the opportunity to spend two days in Kristina's classroom. The day before Joey's visit, I spent an hour answering any questions the children cared to ask—and they asked a lot of good ones: How did you find out Joey had a disability? How did it happen? How does Joey learn? Why can't ke talk very well? What will he do when he's finished with school?

I was able to share what it is like raising Joey: the stress involved in meeting his physical and medical needs, and the frustrations of dealing with others who are impatient with him because they do not understand his limitations, the difficulties understanding what he tries to say—as he repeats the same phrase over and over, even when we don't "get it." But I was also able to share the joys: getting a big hug, watching him eat a whole pizza while saying, "Joey's favorite," knowing that Joey's grandparents, aunts, uncles and cousins really like him, just the way he is.

When Joey visited Kristina's classroom, all the children, as well as the teacher and principal, made him feel welcome. They included him in the things they were doing, and he showed them some of the things he can do.

We had a wonderful time learning about each other. I hope the children gained a deeper understanding of someone who may have limitations, yet enjoys a lot of the same things they do. It was a fun way to share the reality of our family's life with Joey and make the book more "real" to the children.

-Cindy Ferrini

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to:

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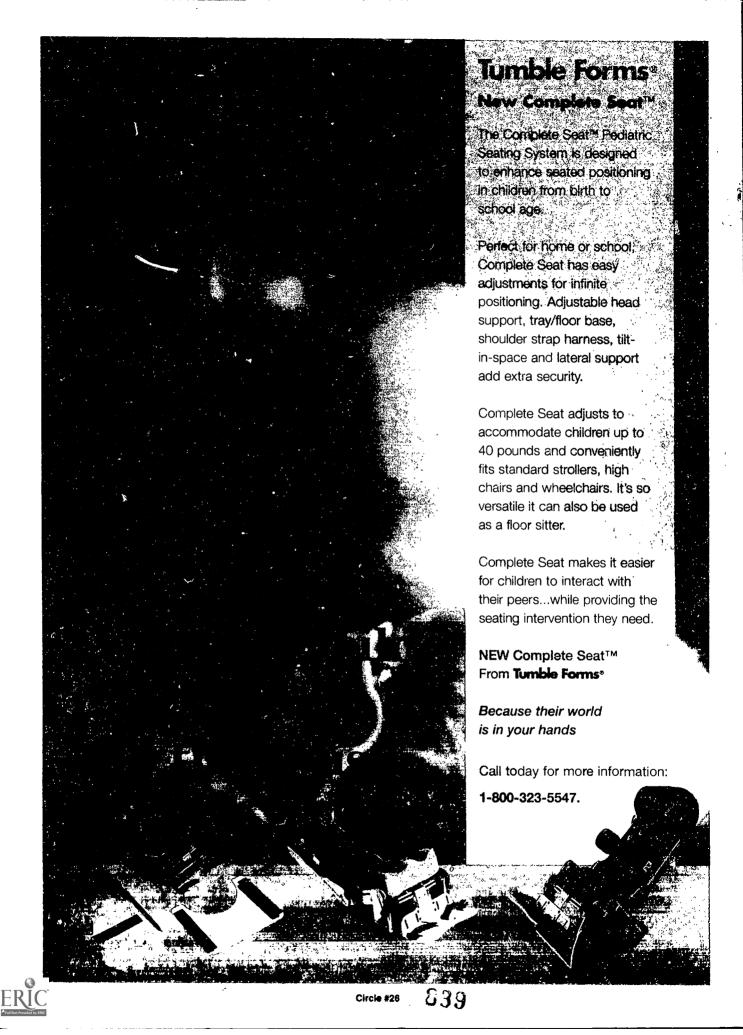
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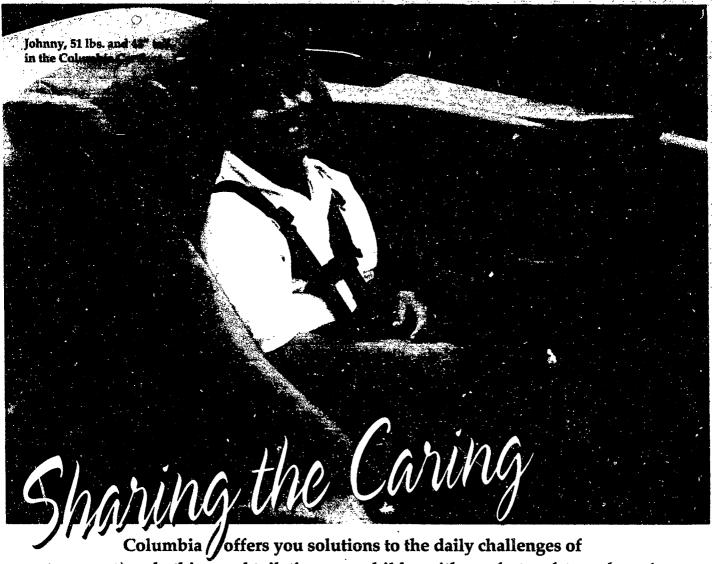
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Contents

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PAGE 20

# CHOOSING TOYS

Using Ordinary Toys for Kids With Special Needs: Great Holiday Gifts by Joanne & Stephanie Oppenheim	26
Rubber Balls, Toy Cars and Art Supplies by Annette B. Heim	31

# **Features**

. 64(4) 65	
Ramps and Lifts	34
Meeting home access needs.	
Beyond Labels by Karen Levine	38
Guest Editorial: Fighting For Our Lives by Bob Williams Legislative cuts threaten our children's futures.	4

# **Departments**

Editor's Desk	2
Letters	4
Search & Respond	8
Familiar Faces	18
Fathers' Voices: Accepting Pinoceillo by Gregory Burns	20
Role Models: Frank Bernard Jr	22
Informational Forum: Networking	49
Children's Health Notes	51
Media: Parent Survival Manual	55

Health Insurance Troubleshooter: HEALTH INSURANCE FOR FEDERAL EMPLOYEES	56
New Products	57
Directory of Advertisers	58
Ask the Doctor: UNEXPLAINED HEALTH PROBLEMS	61
Exceptional Parent Library	62
What's Happening	64
Children's Page: THE KARATE KID by Barry Atkinson	68



PAGE 18



Cover: Barry Atkinson, 11, studies karate at United Studios of Self-Defense in his hometown of Huntington Beach, California. Well on the way to his goal of attaining a black belt, Barry currently holds the rank of orange belt, and last spring, won a trophy competing in his first karate tournament.

Barry has spina bifida with the Amold-Chiari malformation of the brainstem and cerebellum, hydrocephalus, a gastrostomy-button and a tracheostomy. He lives with his foster parents, Ann Belles and Mark Andrews, and is a fifthgrader at Moffett Elementary School in Huntington Beach. Barry's article, "The Karate Kid," appears on this issue's Children's Page. Photo: Alex Garcia.



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# EDITOR'S DESK

# Tovs!

We had so much fun preparing previous features on toys (October 1994 and June 1995) that we've once more invited Joanne and Stephanie Oppenheim to help our readers prepare for holiday shopping by sharing suggestions for ordinary, off-the-shelf



STANLEY D. KLEIN, PH.D.

toys that children with disabilities can enjoy with little or no adaptation. But before you hit the toy store with wallet in hand, Annette Heim's account of her son's best-loved toys ("Rubber Balls, Toy Cars and Art Supplies") will remind you not to overlook some of the old favorites.

# Diagnostic labels

When parents first hear the clinical diagnostic terms used to describe a child's disability, the words can be terrifying. Sadly, these diagnostic labels are sometimes used to lower expectations

or exclude youngsters from opportunities. But as Dr. Karen Levine's article "Beyond Labels" illustrates, knowledge of specific disabilities can be used to help a child draw on his or her strengths while overcoming or working around challenges.

# **President's Committee on Mental Retardation**

In early September, I traveled to Washington, DC to attend the 1995 National Collaborative Academy on Mental Retardation sponsored by the President's Committee on Mental Retardation. Although many in attendance were concerned about the political climate, including potential changes in legislation and/or cuts in funding, the active participation of "self-advocates"—adults with mental retardation speaking for themselves and working collaboratively on planning teams made this a truly inspiring meeting. In November, the "Role Models" department will feature one of these young self-advocates.

The growth of self-advocacy illustrates a changing perspective about community services for adults with mental retardation and/or developmental disabilities-a perspective that focuses on individuals and encourages self-determination. Reports at this conference demonstrated many ways in which individual states have moved beyond slogans to thoughtful action. A number of new programs are enabling adults to make choices about their own lives. For example, more and more adults with disabilities are being invited to serve on planning committees, and adults with mental retardation are becoming home owners and taxpayers.

Also at the conference, Bob William's, commissioner of the Administration on Developmental Disabilities, addressed current concerns about the political atmosphere in Washington. Thanks to Bob's quick work with us, we were able to adapt his stirring address, which he delivered with his augmentative communication device, as a guest editorial in this issue (see page 45). And for still more on the political scene, see Networking on page 49.

While in Washington, I also learned that Speaker of the House Newt Gingrich has established a House Task Force on Disabilities. For more information, see What's Happening on page 64.

# Let's celebrate!

In 1996, we will mark Exceptional Parent's 25th birthday! Exciting plans for extraspecial issues are in the works—we welcome your ideas and suggestions. We are even exploring the possibility of a trip for families to a fun place like Walt Disney World. This would take place in October 1996. We need to hear from readers who would be interested in joining us, so we can determine the best possible prices for travel and accommodation packages. Please write to Disney Trip, Exceptional Parent, 209 Harvard Street, Ste. 303, Brookline, MA 02146; (617) 730-9742, fax.

843



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Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription and advertising information, see page 58



# MOST PARENTS OF BED WETTERS THINK THERE IS VERY LITTLE THEY CAN DO TO HELP.

Some 3 million children, 10% of all kids between 5 and 10, wet the bed twice a week or more. If your child is in school, chances are at least two of his classmates are in the same leaky boat. No child should ever feel alone with this problem. But, of course, they do.

The good news: More is known than ever before that can help. Once, the only sure cure was time. 99.9% of our children leave this problem in the dust as they grow. And now there are some new ways to give time a hand.

# THE BEST BEGINNING

For starters, pediatricians know a lot more about the causes of "enuresis" (that's the official medical name for it) than they used to.

Doctors today deal with this problem all the time. They have new techniques and sometimes medicines that can help manage bed-wetting, if not eliminate it altogether.

And now (finally!), there are pants you can buy that can make a real difference at your house, every night and every morning. Your child will still wet. He can't help it. But from now on, that doesn't have to mean he has to wet the bed.

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people have done everything possible to make these absorbent underpants respect our kids like the grown-ups they soon will be.

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GoodNites are not a miracle, but there's nothing like them. They help families keep bed-wetting in perspective. They help make dry mornings, in crisp clean sheets, routine. And make sleep-overs and other normal, healthy everyday kid things routine, too. The way they should be.

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# LETTERS

# **Appreciates definitions**

I just wanted to let you know I really appreciate your recent efforts to explain more about disabilities mentioned in the magazine, particularly in Search and Respond. I'm always interested in learning more about the various "realities" people live with as "exceptional parents," but am usually too lazy to go look up information about disabilities I am not familiar with. And frankly, some of these conditions are so rare, I wouldn't be able to find them in the books I own anyway. Your extra efforts in this regard make your magazine much friendlier and much easier to read.

J.W.P., North Carolina

# **False Accusations of Abuse**

Writing in the August 1995 issue, B.T. of Connecticut responded to the May 1995 article on facilitated communication by saying, "I would rather see someone falsely accused of abuse than see a guilty person not be accused."

I am appalled by this statement!
What an attitude—"shoot them all and

let God sort them out." Far too many people have been falsely accused of abuse; their reputations have been ruined, their lives shattered. In B.T.'s philosophy, they are expendables.

Contrary to B.T.'s belief, we cannot assume children are always truthful. We must consider the possibility that a child may be imagining something, or even outright lying.

I've been the victim of a person who needed to invent this type of situation.

Tom Carten Wilkes-Barre, Pennsylvania

# **Ketogenic Diet**

I have read with great interest your coverage of the ketogenic diet for the control of seizures (*Letters*, June 1995 and *Ask the Doctor*, July 1995). Your Editor's Note following the letter in the June issue states that the diet is "used most often with children aged two to six." Although it may be true that some older children will not like the diet's restrictions, I think most would be willing to try anything for the possibility of being seizure-free and medication-free for life.

In July's Ask the Doctor column, Dr. Hirsch says, "This diet should not be the first choice among options for seizure control..." Why not? I wish I had known about the ketogenic diet four years ago, before we went through four medications, thousands of dollars and too many neurological tests to count. Why would any parent choose a lifetime of seizures, medications and blood tests over two to three short years of following a strict diet?

My nine-year-old daughter, Renee, began the ketogenic diet on June 27, 1995. I can't even begin to tell you about the wonderful changes that have resulted. Best of all is *no more* seizures! Renee is never hungry or thirsty; in fact, I have to keep reminding her to drink all of her allotted liquid.

Last week, I asked Renee if she wanted to go back to eating all the things she ate before. Her reply was an emphatic, "No way! I want off these pills!"

I believe every parent of a child with epilepsy should be given the opportunity to try the ketogenic diet. It should be the duty of every neurolo-

continued on page 6

# EXCEPTIONAL PARENT To Make the Law Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the Control of the C

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PEGGY MANN RINEHART, B.A., Parent, Director of Communications, Center for Children with Chronic Illness and Disability, University of Minnesota, Minnespolis, MN

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B. J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI

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CAROL TINGEY, Ph.D., Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

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# PRODUCT NEWS



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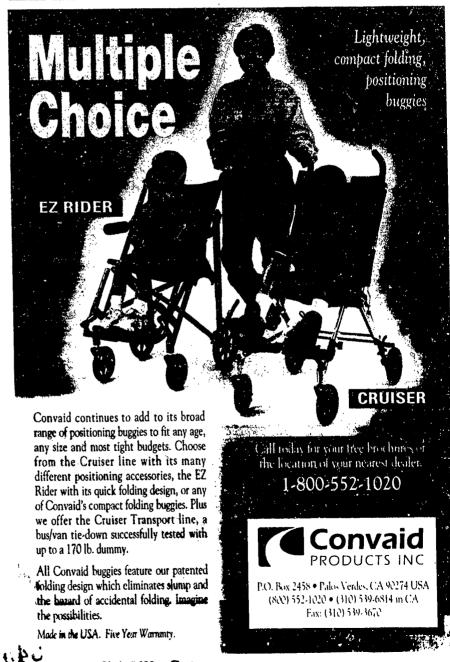
Now available, the Cruiser Transports, a new bus/van tie-down buggy line from Convaid, successfully crash tested at 30 MPH, 20g decel in a forward-facing configuration with up to 170 lb. dummy, using a Q-Straint (with positive lock) tie-down.





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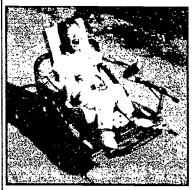




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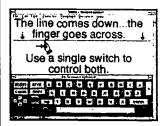
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Circle #80

# EXCEPTIONAL PARENT / OCTOBER 1995

# LETTERS

continued from page 4

gist to inform patients of *all* treatment options for seizure control, not just "drug therapy."

In addition to the resources listed in July's *Ask the Doctor*, I would also like to tell parents about the *Keto Klub Newsletter*; which provides information and helpful ideas about the ketogenic diet.

Lisa Smith St. Joseph, Michigan

DR. HIRSCH RESPONDS: I am always happy to hear about successful therapy for seizure disorders. In many individuals with seizures, a single anticonvulsant will be effective, and have few or no side effects. For those individuals, this option for seizure control would be safer and easier to manage than a ketogenic diet. However, if a seizure disorder appears very complicated or intractable (hard to control)—and this should become clear within two years—a ketogenic diet would be a reasonable therapeutic option.

EDITOR'S NOTE: Subscriptions to the KETO KLUB NEWSLETTER, published quarterly, cost \$20 in the U.S., \$25 in Canada and \$30 for other countries. For a free sample copy, send a self-addressed envelope with a 32¢ stamp to KETO KLUB NEWSLETTER, 61557 Miami Meadonvs Ct., South Bend, IN 46614.

Fragile X Syndrome and Genetic Counseling

I was so excited to son the June 1995 issue in which the *Ask the Doctor* column dealt with fragile X syndrome. It seemed like a giant step forward in our goal to increason public awareness of the leading cause of inherited developmental disability. But two months later, reading the article "Genetic Counseling" (August 1995), my heart sank. In that article, a clinicial geneticist listed the types of families who might benefit from genetic counseling. But that list of candidates for counseling did not include families with a history of unexplained mental retardation or autism.

The genetic counselors and geneticists who advise our parent group would certainly disagree. Please set the record straight and let's take another giant step forward together.

Mary Seward, President Fragile X Association of Southern California

Entron's Note: Thank you for your letter. Our experts agree with you.

# Tell us about...

# ... your child's experiences (both good and not so good) at summer camp.

What type of camp(s) has your child attended? How did you choose the camp(s)? If your child has attended a "regular" camp, what adaptations were made?

Write to: Readers Talk, Exceptional Parent, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fux). A sampling of reader responses to this question will appear in a future issue.









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# SEARCH

# Rh Incompatibility

Surely, there has to be another family in this country who can relate to our situation! My husband and I have incompatible blood types due to the Ph factor. I am Rh negative: he is Rh positive. We have two children. Throughout both pregnancies, I received excellent prenatal care, including Rhogam shots to prevent any sensitization between my blood type and my child's blood type should they have inherited their father's Rh positive blood (both did). We thought we were safe until 38 weeks into my second pregnancy, I found myself being rushed off for an emergency C-section.

My daughter, Rebecca, spent six and a half weeks in the NICU with serious problems caused by Rh incompatibility, also known as hemolytic disease of the newborn or erythroblastosis fetalis. Her spleen and liver were enlarged, and because her liver was not functioning well, she had hyperbilirubinemia (jaundice caused by excess bilirubin in the blood). Things got so bad, we had her baptized.

Now Rebecca is 21 months old and has cerebral palsy. She can't do anything for herself. Her independent sitting is poor, and she can't stand, crawl, creep, walk or talk. Doctors told us that because I'm now producing antibodies to Rh positive blood, any future pregnancies will be affected by this disease.

We know that prior to the availability of Rhogam, more children were affected with Rh disease. Does anyone know them? Or is anyone going through this now? We'd love to talk to them because we have a lot of questions.

G.C. & S.C., Connecticut

# **Congenital Muscular Dystrophy**

Our four-year-old daughter, Olivia, has been diagnosed with congenital muscular dystrophy. She has generalized gross motor weakness, but her fine motor skills are normal. At birth and throughout infancy, Olivia appeared average in every way but did not achieve milestones. She could not

hold her head up, crawl or use her arms or legs to support herself. By nine months, if placed in a sitting position, Olivia was generally able to maintain that position, but if she fell over, she could not get up.

At the age of 13 months, a blood test showed that she had extremely high levels of CPK (creatine phosphokinase) in her blood. An EKG (electrocardiogram) and EEG (electroencephalogram) were normal. An MRI (magnetic resonance imaging) of the brain showed some anomalies. Finally, a muscle biopsy was done. Although the results were not clear-cut, doctors concluded she had congenital muscular dystrophy.

At 18 months, Olivia began physical therapy. She can now crawl a short distance and is starting to climb on and over low objects. She also scoots on her rear end. She uses a manual wheelchair outside our home and in preschool. She is potty-trained, intelligent and happy.

Olivia's doctors cannot tell us whether she will continue to progress or start to regress. They cannot tell us if she will be able to walk on her own. They cannot tell us the chances of having another child with this condition.

We are looking for parents whose child has the same or a similar diagnosis. We want to know how they approach day-to-day life, what sort of school their child attends and whether they have had other children—"normal" or with the same diagnosis.

C.D., California

# Undiagnosed

I'm interested in finding someone who may know what's wrong with our son, David. He is a three-year-old, white male with hypotonia (low muscle tone), scoliosis (curvature of the spine), cataracts and nystagamus (involuntary, rapid eye movements). The results of all the tests and muscle biopsies done have come back negative.

David seems to understand simple commands, such as "give me a kiss." But over the last six months he stopped eating solid foods and cut back on the amount of milk he would

continued on page 12

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Through the years, caring Heartspring professionals, working in interdisciplinary teams, have developed successful programs to meet the very special needs of each child.

This year, Samantha learned that self-injurious behavior wasn't necessary to communicate her dislikes; she learned there were better ways to communicate. Daniel learned to communicate his thoughts and ideas through a combination of picture boards, sign language, and computer technology. And the list goes on.

If you know a child who might benefit from Heartspring's programs, or if you would like to know more about the new campus, call today. Together we can build a brighter future for your child.



Photo courtesy of Madeline McCullough and Ric Wolford



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853

# SEARCH

continued from page 8

take. Now he is continuously fed by NG-tube (a feeding tube that goes through his nose to his small intestine). But it doesn't seem to be working—he weighs only 20 pounds and continues to lose weight. He is also regressing in other skill areas, particularly gross motor skills. He cries so much during therapy sessions that I wonder if it is worth putting him through the pain. Otherwise, he is a very good-natured child.

D.C., Indiana

# **Toilet Training Equipment**

I am an occupational therapist in a public school. I am looking for a source for "high-tech" toilet-training equipment (for example, moisture-activated switches that can be placed in underwear and potty chairs that play music when a child urinates). Such equipment would allow for immediate reinforcement of the desired "behavior" and minimize time spent on the potty chair. I would appreciate any leads on these types of items.

S.S., Illinois

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a chiki or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

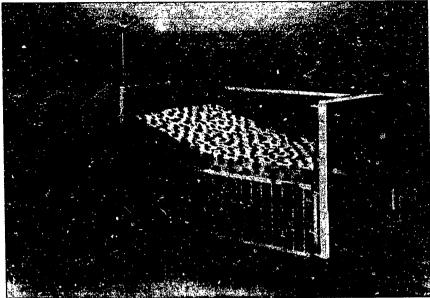
Write or fax: Search or Respond, Exceptional Parent 209 Harvard Street, Suite 303, Brookline, MA 02146-5005 Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in Exceptional Parent's 1995 Resource Guide (January 1995).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-5-40 (Fax).

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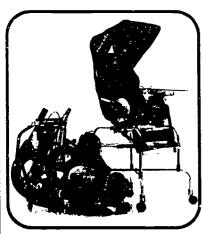
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# RESPOND

# **Self-stimulation and Smearing**

K.D. (July 1995) has a 10-year-old daughier, Aimee, who has severe mental retardation, is nonverbal, has an uncontrollable seizure disorder and wears diapers. K.D. was looking for advice on controlling Aimee's habit of "masturbating" until she had a bowel movement, then "body painting" with her own feces.

I am an occupational therapist (OT) who has worked with another child who smeared feces. Here are suggestions that worked for us:

- Set up a routine that could substitute for the smearing: Give her body rubs with body oil, and hand rubs with stronglyscented oil or lotion. Be sure to do the substitute "treatment" frequently and regularly, so it is predictable to Aimee.
- Use tight (lycra/spandex) work-out clothing over Aimee's diaper: Footed tights plus a one-piece "unitard" on top should make it difficult to get fingers inside the diaper. With a cloth diaper underneath, this outfit could also be used for swimming.
- At swim-time it would not seem inappropriate for Aimee to wear a rubber inflatable ring with a sling seat, the type used by small children. Perhaps your OT could help make it snug enough that Aimee has trouble reaching under or around it. This ring could also be used at home during playtime, but not in bed.

We have had the most success by expecting any habit, such as self-stimulation, to be under control while the child is with others, rather than expecting it to be eliminated at all times.

J.O., Connecticut

# Waterbed?

D.S. (July 1995) wonders if her one-year-old daughter, who has spastic quadriplegic cerebral palsy and limited movement, is comfortable sleeping on a flat mattress. D.S. was considering the purchase of a waterbed and wondered if other parents could share their experiences.

Our son is 10 years old and has multiple disabilities. He is deaf and blind, and has hydrocephalus, a seizure disorder and spastic quadriplegic cerebral palsy. When Michael was 18 months oid, he began banging his head in his crib. At that point, we decided to buy him a waterbed. We hoped it might stop his head banging, and we also thought it might be more comfortable and provide him with different sensations.

The bed we purchased had a semi-waveless mattress, which allows only a minimal amount of motion. But soon after getting the bed. Mike learned how to move around with the small movements of the "waves." Within six months, he began crawling.

Today, Mike can walk with assistance and can pull himself up to stand. His multiple disabilities limit him greatly, but all things considered, he is doing quite well.

J.R., Illinois

■ We have adopted three children. All three have spastic quadriplegic cerebral palsy.

Our two older children came to us when they were less than one year old; neither had any movement at all. We immediately

continued on page 16

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continued from page 14

put them in free-flow waterbeds, watermattresses that do not control "waves." They both benefited greatly from the immediate reinforcement they received for even minimal movements. Now, our 16-year-old son "scoots" all over our home and our nine-year-old son rolls where he wants to go. Neither one has significant contractures or scoliosis. I believe the integrity of their musculo-skeletal systems is a direct result of

the movement that was encouraged by use of their waterbeds at night, along with proper, secure positioning during the day. Our newest child, a one-year-old, has been in a waterbed for six months, and is now starting to push her foot against the side to rock herself.

R.R. & P.R., Florida

■ Even before our child was born, we knew he or she would sleep on a

waterbed. I was the owner of a bedroom store specializing in waterbeds.

Our son was born with spastic quadriplegic cerebral palsy. Because I worked in the industry, I was able to have a custom-built frame and watermattress made for him. Because we worried about him rolling out of bed, we installed a clear Plexiglass wall on the side—about 10 inches higher than the top edge of the frame. While protecting him, it allowed him a clear view of the room and everything that was going on around him.

We believe that the warmth provided by the heated waterbed helps his muscles to relax while he is sleeping. A waterbed is not a cure-all; he also attends occupational and physical therapy sessions and is involved in a horseback-riding program.

Over the years, we've also noticed that our son sometimes develops pressure sores after hospital stays. This has never happened at home where he uses his waterbed. In the waterbed, he can sleep all night without needing to be turned.

I am a member of the board of directors of the National Waterbed Council (236 Rte. 38 W., Ste. 100, Moorestown, NJ 08057), which can provide additional information about waterbeds. The Council's sister organization, the Flotation Health Care Foundation (5757 W. Century Blvd., #512, Los Angeles, CA 90045) can help provide waterbeds to individuals who need one for a medical reason, but lack the necessary financial resources. You may write to these organizations for more information.

I would also like to offer my assistance to any Exceptional Parent reader. I can provide information or referrals to helpful waterbed dealers.

D.M., Indiana

EDITOR'S NOTE: Readers wishing to take D.M. up on his offer of assistance may write to him c/o
EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146.
On the lower, left-hand corner of the envelope, please include the words, "ATTN: Waterbeds." We will forward all letters to D.M.

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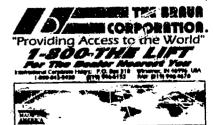
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# Familiar Faces

Five-year-old buccaneer Rachel Leanna Tung, of San Francisco, California, paused from her pillaging to smile for the camera. Rachel, now 7, has undiagnosed developmental delays and low muscle tone, and was born with a cleft palate. She attends Ulloa Elementary School in San Francisco. "She has lots of friends there," writes Rachel's mom, Linda. "She really enjoys school."





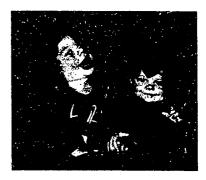
Young dragon **Brendon Kirsch of** Sherman Oaks, California, carefully guards his bag of Halloween goodies. Brendon, 17 months, has cerebrai palsy. "He enjoyed strolling through the local mail in his costume," writes Morn Marcy. She adds that the scaled suit was "iovingly made" by his babysitter, Hilda Cabrera, of Van Nuys, Call vinia.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!



Six-year-old Jeremy Latta (right) is ready to trick-ortreat 'til the cows come home! Jeremy, shown here with sister Ashley, 4, loves cows. "The one sound he can make clearly is 'moo,'" explains his mother, Janice. "When he put on his costume, he absolutely bearned with joy." Jeremy, of Plymouth, Massachusetts, has chromosome XYY, autism and a seizure disorder.

Elyse Ritter, 2, (left) of Columbia, South Carolina, and her five-month-old brother, Adam, celebrated Hailoween 1992 in style. "We think they made adorable pumpkins," write their parents, Stephen and Frieda. Adam liked life as a pumpkin so much, he stuck with



that theme the following Halloween, but Elyse decided to branch out and don the garb of Snow White. The Ritters describe themselves as "big fans" of EXCEPTIONAL PARENT. Elyse has cerebral palsy.

Jason Montgomery, 14, of Pemberton, New Jersey, takes his Halloween costume, the "SS Jason," on its maiden voyage. Jason's mom, Carol, writes that her son's wheelchair float, inspired by **EXCEPTIONAL PARENT'S** September 1994 article "Halloween Magic," was the first of its kind at his school-**Burlington County Day** Training Center in Mt. Holly, New Jersey-and a big hit with teachers, who found it easy to wheel him from class to class for trick-or-treating. Jason has Angelman syndrome.



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# rathers' Voices



Camryn, 13 months, enjoys a walk in the rain with Dad.

ave you ever been taken by surprise by your emotions? It happened to me recently, when I saw a promo for the movie *Pinocchio*. All of a sudden, I found myself dealing with a whole set of feelings I had packed away and pushed to the back of my "emotional garage"—one of these days, I've got to clean that place out!

That movie promo brought me back to the moment my wife and I learned that one of our twin daughters had a chromosomal disorder. That day, as the doctor spoke, there was a part of me that wanted Camryn to be a "real" girl, in the same way Geppetto wanted Pinocchio to be a "real" boy.

I knew children with disabilities were held up not with strings, but with I.V. lines, braces and medication. They were also held up by their parents. But Cary and I were so unprepared. Who was going to hold *us* up?

Several years later, looking back at those feelings, I know what held us up—our friends, our family, our faith and networking with other parents. Sometimes Cary and I held each other up; other times, we simply "held on" because we had no choice.

Understanding helps, too—understanding that it's okay

to have a child with a disability. By now, however,

Accepting Pinocchio

Maybe we can learn to be "real" parents
by Gregory Burns

my wife and I have gone beyond "okay" to realize we have been truly blessed. It's ironic, but if people were judged by how loving they were, kids like Camryn would finish first in the human race.

Maybe we have near something to

Three-and-a-half-year-old twins Camryn (left) and McKenna enjoy "snow surfing" near their home in Issaquah, Washington.

learn from our "Pinocchios." Maybe they can teach us to be "real" parents. Knock on wood.  $\ensuremath{\mathbf{EP}}$ 

Gregory Burns lives in Issaquah, Washington, and works for Microsoft Corporation. His wife, Cary, is a full-time mom.

They are the parents of four-yearold twin girls, Camrun and McKenna. Camryn has ring chromosome 14, a rare genetic disorder that causes seizures and developmental dclays. There are fewer than seven known cases of the disorder in the U.S.



According to her dad, Camryn just loves people—especially Grandpa Richard Rums.

Gregory Burns dons a party hat to help daughters Camryn (left) and McKenna (right) celebrate their second birthday.



Fathers' Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fux). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

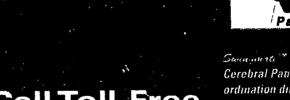
# Special Children... Deserve Exceptional Treatment



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Frank Bernard Jr.

His comic strip finds humor in disability

Frank Bernard Jr., 28, is a cartoonist and the creator of "Funny as a Crutch," a comic strip series about the misadventures of Frankie, a young boy who walks with crutches, and Sharpton, his trusted porcupine companion. Bernard, who has spina bifida, attended the Massachusetts College of Art for two years. He created "Funny



as a Crutch" in hopes that its readers would become more comfortable around people with disabilities. The comic strip currently appears weekly in a local Massachusetts newspaper, THE CHELSEA RECORD.

Bernard explains that he earns the bulk of his "cartooning income" doing caricatures at weddings, parties and other social functions. He also does occasional political cartoons for newspapers in the greater Boston area. In recent years, Bernard has become increas-

ingly interested in animation. He would like to find work with an animation studio, maybe even move up to Disney one day. His short-term goal, however, is to have "Funny as a Crutch" syndicated. The following was adapted from an interview between Bernard and Michele San Filippo, an Exceptional Parent editorial intern.

was born with spina bifida, meaning my spine was not fully developed. The doctor who delivered me didn't think I'd live past the age of two. My parents, Frank and Mary, really didn't believe that. They have always had a lot of faith in me.

Six hours after birth, I underwent the first of about 20 surgeres, this one to repair the opening in my spine. At six months, I had a shunt put into my head to drain spinal fluid that otherwise would go to my brain and kill me.

My parents have always been very loving, but they tend to be a bit overprotective. When I was growing up, they didn't give me much independence. They now drive me around to jobs doing caricatures at parties and weddings. Sometimes they want to give me rides when I don't need them. They always panic when I say, "No thanks. I'm taking the train."

**Getting started** I used to hate art as a child. especially painting because it was messy. But cartooning looked like fun. At eight, I began doodling while watching cartoons on television. Bugs Bunny was the first character I learned to draw.

In fifth grade, I started drawing cartoons for the student newspaper. I invented characters like "Tippy,

the Tiger" and "Harvey, the Dog Catcher." But I got my first real taste of cartooning "stardom" when I was in seventh grade at Our Lady of the Assumption School.

A friend of my mother's visited the school and saw me doodling. That afternoon, she took me down to the local newspaper, The Chelsea Record, and showed my work to the editor. The editor said to me, "You're in, kid." So I got my first gig when I was 12, and the paper published my work periodically from 1979 to 1981.

# Trying to fit in

In 1981, I started high school. It was a very difficult experience because of social and physical obstacles. Chelsea High School had three floors and no elevators. People would sometimes help me carry my books, and I was given extra time between classes, but it still was very difficult.

The physical barriers at Chelsea High became such a distraction that in my junior year, I transferred to the high school in nearby Saugus, Massachusetts, because that school had only one floor. But although this move removed some physical barriers, it added new social barriers. I was no longer in my hometown; I suddenly had to adapt to a new school with unfamiliar teachers and students. Luckily, I made some friends who helped me along the way.

But I was never really comfortable at Saugus High, and my grades showed it. I should have graduated in 1985 but didn't have enough a lits. I returned to Chelsea High for my senior year and graduated in 1986.

I had many friends who accepted me the way I was, but there still was some teasing. I tried to fit in. I tried to get people not to see my crutches. I would play baseball by dropping the crutches and throwing the ball around. I couldn't

> run, but I still tried to participate in athletics.

I would always explain my disability to friends immediately. Some were comfortable with the discussion; some weren't. I couldn't believe that there were

Four-year-old Frank (front) gives older brother Christopher, 6, a ride around the livingroom on the back of his toy moped.



people who actually thought spina bifida was a disease you could catch. A lot of people still aren't comfortable around me, and it bothers me. That's one of the reasons I started doing "Funny as a Crutch."

# "Funny as a Crutch"

During the summer of 1986, I was trying to come up with an idea for a comic strip when my mom suggested I do one



Frank, celebrating his fifth birthday on April 30, 1972, shows he can blow out a candle from any position. At the time, he was in a chest-to-ankle cast following surgery to insert plates in his hips.

about having a disability. My first reaction was, "Are you out of your mind? Who would want to read about a depressing subject like having a disability?"

But then I thought, "It doesn't have to be depressing." I could do a comic strip about trying to find the humor in having a disability.

Before I even wrote the first strip, I tried to come up with a name for the series. That was when I recalled hearing on the television show "Happy Days" the expression "funny as a crutch," which meant "not funny at all." The phrase was perfect because it included both the words "funny" and "crutch."

Then I came up with the characters. The lead character's name would be Frankie, just like me. Frankie's best friend, Spike, was derived from friends of mine who were into punk rock. Spike had a mohawk hairdo. Frankie also had a pet dog named Bernard. After a few years, however, I decided to drop Spike and Bernard from the strip.

I wanted to give Frankie a new pet. I didn't want "Funny as a Crutch" to be just another of those boring boy-and-hisdog comic strips, so I started trying to think of an animal that had some type of disability. The first one that came to mind was a skunk, but there's already a cartoon skunk, "Pepe Le Pew." So I went with my second choice—a porcupine. Animals go out of their way to avoid porcupines because of their sharp quills, just like many ablebodied folks go out of their way to avoid people with disabilities. I named this new character "Sharpton," after the Reverend Al Sharpton.

Currently, the strip highlights the interaction between Frankie and Sharpton. Sharpton is Frankie's best friend.

continued on page 24

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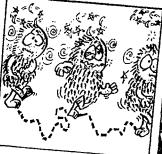
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continued from page 23

Having somebody to confide in all the time was something I didn't have growing up. In a way, Sharpton takes care of that for me.

### Achieving success

In 1987, I showed "Funny as a Crutch" to my old friends at *The Chelsea Record*, but they told me they couldn't use it. In 1988, *The Chelsea Weekly News* decided to use the strip, but that newspaper folded a few months later. But in 1991, my strip made some breakthroughs. First, I sent it to the Massachusetts Spina Bifida Association, and they published it in their newsletter. Then I sent it to *Insights*, a rational publication for people with spina bifida, and they started using it. Finally, *Editorial Humor*; a national cartoc sing publication, did a full-page feature on the strip but stopped short of agreeing to publish it on a regular basis.

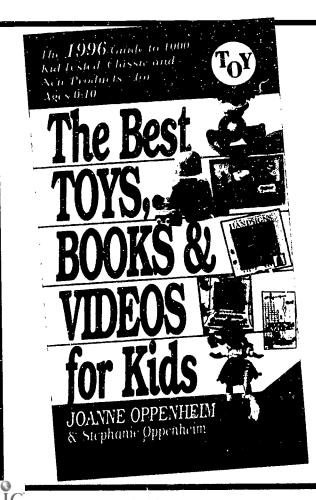
In October 1992, I called The Chelsea Record, deter-

mined to convince them to publish the strip regularly. It took a lot of persistence and nagging, but "Funny as a Crutch" debuted on October 21 of that year and has been there every Wednesday since.

The response has been very good. I've only gotten one com-

plaint—the first year it was published, someone asked how I could make fun of people with disabilities. I answered, "I have a disability. Why would I want to ridicule myself?"

Doing the strip has been therapeutic. I never thought I'd be able to look back at painful experiences in a positive way, but with "Funny as a Crutch," I am able to do that. I hope other people with disabilities will be able to do the same when they read it. Actually though, I'm doing the strip mainly for the able-bodied. If they are enjoying it, I feel confident their attitudes are changing. Hopefully, people who read the strip will learn we're all basically the same. Everyone has disabilities of one type or another. **EP** 



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### USING ORDINARY TOYS FOR KIDS WITH SPECIAL NEEDS

# **Great Holiday Gifts**

by Joanne & Stephanie Oppenheim



For more than 100 suggestions on how to adapt ordinary toys for kids with special needs, see the 1996 edition of **THE BEST TOYS**,

THE BEST TOYS,
BOOKS & VIDEOS
FOR KIDS

(HarperCollins, \$12) by Joanne and Stephanie Oppenheim.

The book is a comprehensive guide to more than 1000 classic and new products for children from infants to preteens, and is available through Exceptional Parent Library (800/535-1910).

s the holiday season approaches, a trip to toyland becomes a must. Before you go wandering down the aisles in search of the perfect gift, take a look at these kid-tested toys; they are entertaining, educational and easy to operate. These are ordinary toys that require little or no adaptation for children with disabilities. Most can be easily found in any toy store. Following the name of each toy, in parentheses, is its manufacturer, the recommended retail price and a customer service number that may be used for ordering or for more information on locating products. Following the description of some toys are suggested adaptations or activity tips.

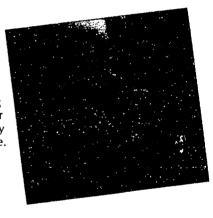
Most of these toys are versatile and will provide various kinds of play for children with different abilities. Although this article categorizes toys by age level, conventional age labels may be less meaningful for children with significant developmental delays.

### INFANTS AND TODDLERS

### FLOOR SPINNER

(Primetime Playthings, \$13.95; 201/831-1400)

Infants and toddlers will find many sights and sounds to explore by turning and manipulating this intriguing floor toy. Each of the four cones has a distinctive activity—beads rattle, a beeper beeps, a mirror reflects and a tracking ball solls through its track. Ideal for two-handed play and fun for crawling infants and toddlers to bat at and chase.





(Learning Curve Toys, \$19.99; 800/704-8697)

Here's a new look to the classic ring-and-post toy. These soft fabric rings are fun to listen to, with their built-in rattles and squeakers, and fun to look at, with their vivid patterns. Although they can be used for learning about size, there is no right or wrong—the rings will fit on the post in any order.

**Adaptation idea:** Sew textures of terry, satin, corduroy or other fabrics to the rings for greater sensory feedback.

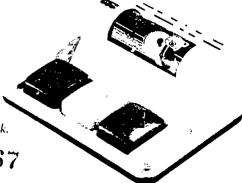
**Activity tip:** Play a "find-it" game. Spin two rings and have child find and grab the biggest ring or the blue ring or the smallest ring.



(Fisher-Price, \$30; 800/432-5437)

This piano allows children to make a lot happen with a simple swipe of the hand. It has three big, light-up keys and a musical chime roller that plays a tune.

Adaptation idea: Add glue textures or Braille dots to each key for tactile feedback.



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EXCEPTIONAL PARENT / OCTOBER 1995

### TANGIBALL

(Discovery, \$9.98; 800/426-4777)

Kids can squeeze, sniff, roll, kick and enjoy this vanilla-scented, soft and squeaky four-and-a-half-inch vinyl ball. The surface is covered with small bumps for multisensory play. Fun to chase. Also great for early social games of rolling the ball back and forth.



### AIRPLANE SWING*

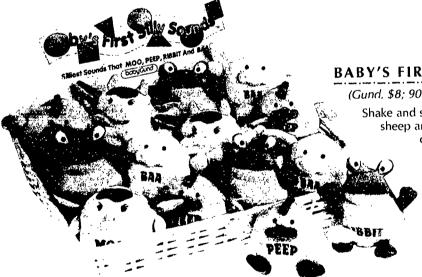
(Little Tikes, \$28; 800/321-0183)

A parent told us how useful this airplane swing, with its high back, has been for her three-year-old child, who needs extra support for sitting. Children practically wear this jolly

airplane—it holds them all around and there is no place to slip through. Has an adjustable seat belt. Can accommodate children up to

* Exceptional Parent featured this toy in "Using Ordinary Toys for Kids With Special Needs: Outdoor Fun" in June 1995. However, we inadvertently ran the wrong photo with the Airplane Swing description. We regret the error.





### BABY'S FIRST SILLY SOUNDS FARM

(Gund, \$8; 908/248-1500)

Shake and squeeze these chubby, ball-shaped toys—a cow, chick, sheep and frog—to make them "moo," "peep," "baa" or "ribbit." They can be linked together by the velcro pads on their "arms." These cute critters are made of terry cloth and sold separately.

> Activity tip: With older tots, use these critters to animate a lively song of "Old MacDonald."

### **DUPLO BABY**

(Lego, \$5.99-25; 203/763-3211)

These colorful stacking blocks with rounded corners are easier to fit together than other plastic blocks. Designed to stimulate the senses, the various box sets include mirrors, cars, people, animals that make rattle sounds and even a rock-and-spin block that twirls like a top. We suggest the Storage Bear set or the X-large Stack 'N' Learn set, which both come with an adapter for use with traditional Duplo blocks.

Activity tips: Use words that describe each object's color, size or position as you play together. Put the toys away by playing a singing color game: To the tune of "Where is Thumbkin?" sing, "Where is red? Where is red? Here it is! Here it is!"



More great holiday gifts on page 28





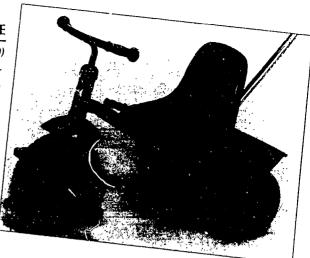
### PRESCHOOL AND EARLY SCHOOL-AGE

### KETTRIKE JUMBO TRIKE

(Kettler, \$109.90; 804/427-2400)

This sturdy red tricycle comes with a high-backed seat for secure sitting and a cargo hold in back. Detachable push bar allows parents to help as children learn to pedal.

Adaptation idea: Add a seat belt, trunk support or foot harnesses to provide extra security. Two companies specializing in products that can be used to adapt riding toys—such as tricycles, scooters and rocking horses—are Sammons Preston, P.O. Box 5071, Bowlingbrook, IL 60440-5071, (800) 631-7277; and Flaghouse, 150 North MacQuesten Pkwy., Mt. Vernon, NY 10550, (800) 221-5185.





(Playskool, \$16.99; 800/752-9755)

This two-sided, magnetic alphabet board comes with 38 letters embossed with Braille symbols. One side has cut-out shapes, in alphabetical order, in which to fit letters. On the other side, children can use letters to make words. Storage space and carry handle are built-in. A 36-piece set of magnetic numerals and symbols embossed with Braille is also available (\$3.99).





### ROLL-A-ROUND PLAYGROUND

(Fisher-Price, \$24.99; 800/432-5437)

Talk about making things happen! There's plenty of playful action built into this pretend setting. Three easy-to-grasp, roll-around critters fit into the working swing, slide, merry-go-round and peekaboo schoolhouse. A chunky, red lever activates the merry-go-round and provides lessons in cause and effect.

Activity tip: Use the action of the toy to reinforce concepts of "round and round," "in and out," "up and down."

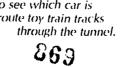
### ADVENTURE MOUNTAIN RACEWAY

(Little Tikes, \$40; 800/321-0183)

This wonderful mountain has six fixed raceway courses—a loop-the-loop track, a twist-and-turn path that leads to a covered mine shaft, and two pairs of side-by-side courses that end with cars speeding off the mountain. This toy is excellent for promoting visual tracking and requires little dexterity to make cars start downhill. Comes with two cars. The mountaintop lifts to store 30 vehicles. Play with this toy on the floor not on a table, where the cars might fly off into children's faces.

Activity tips: Mark cars with numbers and race two at a time to see which car is tastest. Or substitute colorful, giant beads or balls for cars. Or route toy train tracks







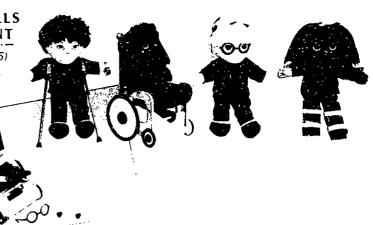
EXCEPTIONAL PARENT / OCTOBER 1995

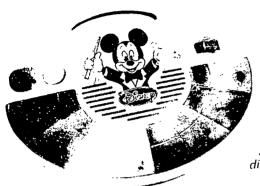
MULTICULTURAL DOLLS & ADAPTIVE EQUIPMENT

(Constructive Playthings, \$7.95-\$39.95; 800/448-4115)

These 15" rag dolls have a younger and more cuddly look than vinyl dolls, and they are easier to bend to fit into a wheelchair. You can select a boy or a girl

from four ethnic groups—Asian, Caucasian, Hispanic or African-American. Adaptive equipment includes a wheelchair, crutches, leg braces and eyeglasses.





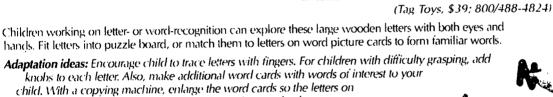
### FOLLOW-THE-LIGHTS KEYBOARD

(Mattel, \$30; 800/524-8697)

Kids can play this Mickey Mouse keyboard in three modes: the automatic mode plays eight tunes; the keyboard mode allows kids to play tunes as they would on a piano; and the follow-the-lights mode guides kids through eight preprogrammed songs by "teaching" them to hit each key as it ights up.

**Adaptation idea:** The lighted keyboard may be helpful to kids with visual disabilities, or Braille symbols can be added to large keys.

I CAN SPELL! ALPHABET PUZZLE



Activity tips: Play a game with letters: Put them in a bag and have child feel the letter and guess which it is before pulling it out. Play sound games with letters: Say, "I'm looking at the sound that starts the words 'pig,' 'pie,' 'Papa.' Can you find it?"

each are the same size as the wooden letters.





MAISY GAME

(Briarpatch \$20.99; 800/232-7427)

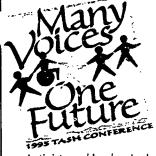
Spin the arrow, then find the object on the board that matches the color the arrow lands on. This game allows children to work on visual matching skills and develop a vocabulary for naming familiar objects. Features Lucy Cousin's storybook mouse, Maisy.

**Adaptation idea:** To make the pieces more secure, place the playing board on a metal cookie sheet. Paste small magnets on back of playing pieces.

Activity tips: Play a sorting game by putting together all the striped pieces, all the red pieces. Play a riddle game by asking child to find "the round thing that rolls or bounces."

These products were reviewed by the Oppenheim Toy Portfolio, an independent consumer organization that tests and evaluates the best products for children. The organization annually publishes THE BEST TOYS, BOOKS & VIDEOS FOR KIDS and also publishes a quarterly newsletter. Both publications include learning activity ideas and ways to adapt ordinary products for kids with special needs. To subscribe to the newsletter, send \$12 to The Oppenheim Toy Portfolio, 40 East 9th, Suite 14m, New York, NY 10003.

1890





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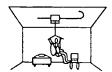






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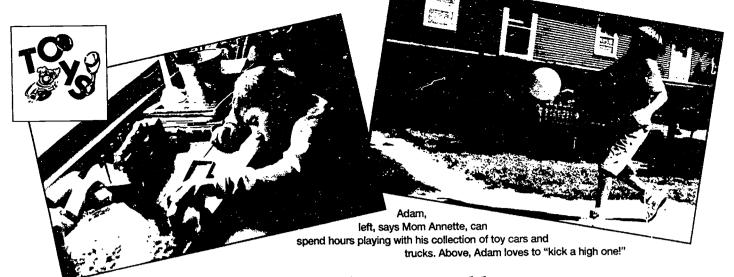
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Circle #39



# Rubber Balls, Toy Cars and Art Supplies

For Adam, the simplest toys are the best

by Annette B. Heim

dam's room looks like a toy store. There are several reasons for this. The first is that my 13-year-old son has an uncanny ability to find the toy department in just about any store, and he combines that ability with several successful tactics of persuasion.

The second reason has to do with a long-standing belief that I could make up for Adam's developmental delays by doing all the "right things." That included buying toys to stimulate and challenge his abilities—things like educational games, a computer and toys to aid in the development of fine- and grossmotor skills. Many of these games and toys have been helpful, and Adam has enjoyed their use. However, his favorite toys, and those most adaptable to his needs, are the most basic and least expensive—things like balls, toy cars and art supplies.

Adam likes balls because he can make them do whatever he wants. The movement of balls is predictable, and this gives Adam a sense of control over at least one object in his environment. In his words, he loves to "kick a high one!" Emotional security, practice in gross motor skills and social interaction—not bad for a simple two-dollar purchase!

Though he loves to kick and throw balls, Adam doesn't yet enjoy structured games requiring greater technique and knowledge. But as he matures, gains confidence and becomes interested in playing on a soccer or baseball team, his early ball play will form a good foundation for acquiring more advanced skills.

Adam's Hot Wheels and Matchbox cars reside in a large plastic box in the living room. They must be close at hand at all times! He has been collecting and playing with these cars for years. He can spend long periods of time "driving" cars along the window ledge, parking them, lining them up, placing them in groups and examining each one minutely. Small cars can be carried to church, to restaurants and in the car. Adam receives immense pleasure from playing with his cars, and we have the satisfaction of knowing that this activity contributes to gains in

fine motor skills, eye-hand coordination, and sorting and matching skills.

A desk in our kitchen overflows with crayons, markers, paints, glues, rubber stamps, scissors, paper and Play-Doh. Adam loves to sit at the kitchen table, art supplies spread out around him, while he draws, cuts and pastes. Art is one of the most adaptable activities possible. Unlike a toy that can be used for only one activity, art materials are subject only to the interests and desires of the child using them.

Art allows children to experiment freely with colors, shapes, mediums and ideas. Because art does not depend on verbal language or great physical skill, it has become a powerful means of self-expression for Adam. He likes to draw pictures of his friends, his family, his dog and himself. As parents, we learn much about Adam and his feelings by observing his artwork.

Adam also uses art to make sense of the world around him. When he visits his grandparents' farm, he draws farm animals. When we moved to the Gulf coast and Adam first saw alligators in the bayous, he drew picture after picture of these new and exciting creatures.

Although art involves an individual process of creation, it often facilitates social interaction. Neighborhood children are attracted to our abundance of supplies, the artist's easel made by Adam's uncle and my willingness to let them "make a mess." Everyone benefits.

What do balls, toy cars and crayons have in common? They stimulate mind, body and spirit; they adapt to the abilities of the growing child; and they are so much fun that they will never gather dust on the toy shelf.

Annette B. Heim lives in Mobile, Alabama, with her husband, Bret, and son, Adam, 13. Annette is a librarian and musician. Adam has partial trisomy four, a chromosomal disorder. This year, for the first time, Adam is being homeschooled.



1

OCTOBER 1995 / EXCEPTIONAL PARENT + 31



Sandy L Chicago Artist C-e quadriplege

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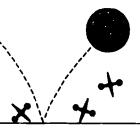
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SENATOR TOM HARKIN



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happen to have epilepsy,
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JONY COELHO, Chairman President's Committee on Employment of People with Disabilities



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ELAINE L. CHAO President and CEO United Way of America



UN





AMERICA'S DISABILITY CHANNEL



ven in areas with relatively flat terrain, access to many community activities—housing, education, health care, transportation and employment—requires moving from one level to another. As a result, despite grad-

ually-changing building and recreational facility designs, children and young adults who have difficulty going up or down stairs can be restricted from participating in day-to-day activities.

Ramps or lifts can make it possible for a child or young adult with physical disabilities to have independent access to his or her home.* In recent years, many access options have evolved. Parents can gather information about these options to determine which one(s) will best meet their child's need for access and their family's budget and space requirements.

### Ramps

Although sidewalks and driveways are often level, entrances



accommodate a straight ramp. "Switch-back" ramps—ramps that make turns—take up less space and may also be more aesthetically pleasing. It is important, however, to have adequate turning space at

In this building, the second floor is as easy to get to as the first. (Photo courtesy of The National Wheel-O-Vator Company, Roanoke, IL) A vertical platform lift makes the entrance to this house accessible. (Photo courtesy of Mac's Lift Gate, Long Beach, CA)

a lift may be the solution. There are three main types of lifts: platform lifts, stairway lifts and elevators.

The first type, the platform lift, allows a child who must remain in his or her wheelchair to go up and down stairs. Vertical platform lifts, which travel straight up and down, can be installed inside or outside, and can be open or enclosed. These lifts usually travel vertically up to 8 feet; lifts that travel as far as 12 feet are also available. The lift must be big enough for a large wheelchair (30" x 48"), and all surfaces on the lift—including the approaches to it on each level—must be slip-resistant. At the top and the

bottom of the lift route, you'll need enough space to open the swinging gate and allow the child to get on and off easily. The person riding the lift must be able to reach and use the controls. For younger children, adults may need to control the lift with a locking system.

Finally, the lift should have a call button to summon help if needed.

A platform lift can also be installed on a stairway. These platforms, called "stairway inclined lifts," are useful if the distance between floors or between stairway landings is too steep tor a ramp. Some stairway inclined lifts fold up, to open up the stairway for people who will not be using the lift. Certain lifts of this type can even be installed on curving stairways.

Residential elevators are another solution for a child who must remain in his or her wheelchair. However,

because they require enclosed shafts and must be installed very carefully so as not to interfere with critical structural elements or roofing systems, such elevators are

A stairway inclined lift is installed directly onto the stairway. (Photo courtesy of Econol Elevator Lift Corp., Cedar Falls, IA)



# Ramps and Lifts

Meeting the need for access



Portable ramps are perfect for traveling—easy to transport and store. (Photos courtesy of Homecare Products, Inc., Kent, WA)

to most homes include stairs. Ramps or graded pathways can make such entrances accessible. These ramps and pathways require the proper degree of slope; a ramp must be 12 inches long for each inch it rises. A steeper ramp is much more difficult to use, and more dangerous. Although a gradual straight ramp is the easiest to use, many homes do not have sufficient ground space to

'Ramps and litts are also available for getting in and out of vehicles, swimming pools, beds and bathlubs, but these products are not described in this article. each point where the switchback ramp changes direction.

Ramps can be made of wood, metal, concrete or asphalt. Whatever the surface material, the ramp must provide safe access, regardless of weather conditions. This means all surfaces must be slip-resistant, even when wet. Building a roof over a ramp is recommended; a covered ramp will also be easier to maintain.

Other necessary safety features include curbs to prevent a wheelchair from rolling over

the edge and handrails to provide security for a child in a wheelchair or one who needs assistance walking. Handrails need to be continuous, easy-to-grasp and slip-resistant. Metal rails are durable, but they ideally should have an insulated coating as metal can become hot in the summer and extremely cold in the winter.

### Lifts

Ramps are a good solution to access needs when there is adequate space. However, if space is too tight for a ramp,

continued on page 36





### A Great Scouting Opportunity.

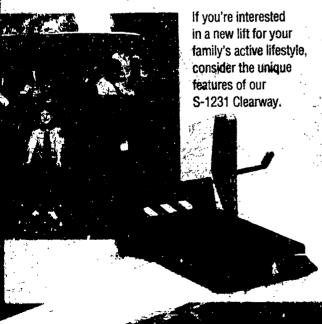
Troop #767SNS (Special Needs Scouts) of Orange County, CA, is just like any other boy scout troop, except for one thing—every member has a disability. Because most of the boys use wheelchairs, their participation in traditional scouting activities is a major challenge...but one they face with pride and determination. The troop,

founded by Bruce Marich, president of Southern California Mobility is currently raising money to buy a mini-bus equipped with a Ricon lift.

Until then, Bruce's personal van installed with the Ricon S-1231 Clearway Wheelchair Lift is ideal for the troop's transportation needs. Its strong steel frame and powerful hydraulic pump provide a fast, secure means of entry and exit for the scouts. And the fully automatic split platform of the Clearway lift folds up and out of the way, leaving the doorway clear for loading and unloading supplies.

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more expensive and less practical than some type of platform lift.

A platform lift or elevator may not be necessary in all cases. When a child with a disability is able to transfer from his or her wheelchair, sit comfortably and safely, and walk short distant

and walk short distances, the child can use a stairway lift with a seat, sometimes called a "seat lift."

The manufacturer or manufacturer's representative usually installs lifts, but may not be able to complete the related electrical work. Other necessary work

may include structural work on the concrete "pad" at the bottom of the lift and carpentry if the lift is enclosed. As with any adaptive equipment, a lift needs testing and service, and parents or teachers who will be operating the lift may need training. Finally, the lift's design and construction must meet local building and fire codes.

Industries, Inc., Grandview, MO)

crete "pad" at the bottom of

Vertical platform

independence

both at home

and in school.

(Photos courtesy

lifts allow

of Access

The material in this article has been adapted with permission from the ADA COST CATALOX; FOR ACCESS MODIFICATIONS, a publication of the Adaptive Environments Center; Boston, MA, in collaboration with R.S. Means, and with the support of the National Institute on Disability and Rehabilitation Research (LRP Publications, Dept. 450, PO. Box 980, Horsham, PA 19044-0980; 800/341-7874, ext. 347; \$39.50 incl. shipping), and from A Consumer's Guide to Home Adaptation (available from Exceptional Parent Library, 800/535-1910).

Industry pricing guides are another important resource for anyone considering ramp construction or the installation of a lift. These guides provide detailed lists of the costs involved, including specific materials, labor and contractors' overhead expenses. Guides are available in some libraries or can be purchased from R.S. Means (P.O. Box 800, Kingston, MA 02364-0800; 800/448-8182 or 617/585-7880; \$19.95-80.00).

### Construction and installation costs

Providing home access through ramps and/or lifts is one more financial burden for the families of children with physical disabilities. Costs are usually tax-deductible as a medical expense, which can help families who itemize deductions, and service organizations or certain government agencies can sometimes help families pay for ramps and lifts. Usually, however, families bear most of the costs themselves. While the do-it-yourself method can help cut costs, it is feasible only for ramps—the installation work necessary for lifts and elevators requires the skill of a trained manufacturer's representative.

Even for ramps, the do-it-yourself method has its limitations. Ramp construction or installation usually requires a skilled contractor who has had experience with adaptive construction. Even highly skilled "non-professionals" may need to consult with experienced contractors or architects.

A range of guides to contractor selection is available to consumers. When considering various contractors, it is useful to get the names of previous customers who have contracted for similar projects, to ask them questions about quality, reliability and cost. Whenever possible, take a look at the work that was done for these customers and have your child go for a "test ride" on their ramp or lift.

877

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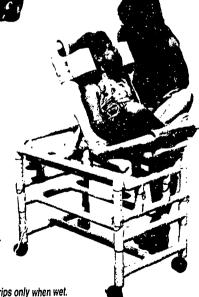
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Bill wanted to help his 10-year-old daughter, Kate, fulfill her dream of learning to ice skate. Bill knew this would be a challenging task because Kate, like other children with Williams syndrome, had coordination difficulties and problems with "motor planning"—the ability to get one's body to move in the complex ways necessary for activities such as skating. On the other hand, Bill knew that a strong sense of rhythm and love of music were characteristics also associated with Williams sundrome. This gave him an idea about how to approach the task. Bill and Kate hit the ice rink armed with a tape recorder and cassettes of Kate's favorite music. Using the rhythm of the music, Bill was able to help Kate learn to perform the smooth movement sequences the activity required. Those "skating lessons" with Dad paid off. Kate, now 16, is an enthusiastic recreational skater who regularly participates in a sport she can enjoy for many years to come.

ome people say, "I don't want to know about the disability. I just treat all children as individuals." But information about a child's specific diagnosis does not have to limit one's expectations for a child. Rather, as Kate's story illustrates, this type of information can be used to guide approaches that will extend the vision of what is possible. Here are some important uses of information related to specific disabilities:

• "Normalization" of unusual behavior: Information about

specific disabilities allows teachers and parents to gain a fuller understanding of unusual or confusing behaviors or developmental patterns. Behavior that might be unusual or disturbing in a typical child may be expected, even typical, for a child with a specific syndrome.

This understanding can prevent misinterpretation and unnecessary searching for the "cause" of confusing behaviors. One example is the common food-seeking behavior of many children with Prader-Willi syndrome (PWS). If another child were to seek food with the same degree of intensity, one might suspect significant emotional problems, poor self-control or even an undiagnosed metabolic disorder. But knowing that this behavior is normal for children with PWS prevents unnecessary concern; it also prevents the placement of blame on the child or family. Parents and teachers who are knowl-

edgeable about the impact of PWS realize they cannot simply "teach" the child not to seek food. Because food-seeking is a biologically-driven tendency in children with PWS, usual behavioral modification techniques just won't work. Knowing this, parents and teachers can move on to exploring strategies for adjusting the environment so that the child's food-seeking tendency causes as few problems as possible. This might mean storing food where it is out of sight or serving food in portions, rather than buffet-style.

Just as important, this understanding of behaviors or difficulties as "normal" effects of a specific disability

# **Beyond Labels**

How to use information about specific diagnoses

by Karen Levine

can be extremely reassuring for the child as well. For example, a teenager with Down syndrome who feels frustrated with her "messy" handwriting may find it reassuring when her teacher explains that most children with Down syndrome have low muscle tone, making handwriting more difficult. This understanding allows the child to correctly identify the source of the difficulty as "out there"—part of the impact of the syndrome—rather than as a personal weakness or shortcoming.

Siblings and classmates can also benefit from knowing that some challenging behaviors are due, in part, to "the syndrome." For example, the sister of a boy with autism may wonder why her brother does not greet her verbally when he comes home from school. She may be reassured to know that this is "normal" for a child with autism.

• Ability to use known intervention or teaching strategies: Information about a diagnosis allows teachers and parents to take advantage of tried-and-true intervention or teaching methods, without having to "reinvent the wheel." For example, although children with Rett syndrome can be challenging to engage, parents who know that music is an intense love for most children with the syndrome have a head start when looking for interesting activities. Similarly, a teacher attempting to design a lesson to hold the interest of a child with Rett syndrome may also take advantage of the child's love of music.

• Availability of support networks: A diagnosis provides access to networks of other parents and professionals working with children who have similar strengths and challenges. Most disabilities with a diagnostic label have regional and national family/professional organizations; many publish newsletters and hold conferences. [EDITOR'S NOTE: The EXCEPTIONAL PARENT

1995 RESOURCE GUDE (January 1995) lists nearly 400 resource groups for specific disabilities. An updated RESOURCE GUDE will be published in January 1996.]

• Increased appreciation of a child's strengths: Many behavioral tendencies associated with the diagnosis of a specific developmental disability may be viewed as positive characteristics by a child. Doers, teachers and family. For example, the social disinhibition and unrestrained emotions often associated with Williams syndrome may add up to a youngster who is an enthusiastic, outgoing and charismatic member of his family and classroom.



Kerry Ann 3ouffard celebrates her 13th birthday with her parents Judith and Richard. Kerry, who lives in Groveland, Massachusetts, has autier: (Photo courtesy of the Autism Support Center, Danvers, MA)

### What about the child without a specific diagnosis?

Many children with developmental disabilities do not have a specific diagnostic label. It is common for parents and teachers to believe that the behaviors such a child exhibits—everything from level of arousal to tantrums—stem from the child's unique personality and experiences. However, even in the absence of a diagnostic label, many behaviors may be associated with biological aspects of the child's disability. For that reason, the strategies and interventions described in this article may be useful for children who do not have specific diagnoses, but whose behaviors and learning profiles are similar to those associated with known syndromes and disabilities.

To better understand and intervene, it will be helpful to ask some basic questions about a child's behavior. How long has the child exhibited this specific behavior or "behavioral style?"

Is it consistent across situations? And does the child have any medical problems? For example, a child who seems to have little energy may be feeling ill, may be depressed, may have some sort of metabolic problem or may have a low level of arousal related to his or her undiagnosed disability.

### Can there be any harm in "labeling" children?

It is important to avoid several potential abuses of diagnostic labels. First, a label should not serve to limit the goals or expectations for a child. In every diagnostic category there are some individuals who exceed all expectations, and whose disabilities have only the mildest of impacts. And *all* behavior is susceptible to environmental influence.

Second, it is important to view a child's diagnosis as just one of many factors contributing to who a child is. Not everything unique about the child is related to his or her disability. All children, with or without disabilities, are influenced by their families, their

teachers, their peers, their life experiences and their  $\nu_{\rm e}$ ological and genetic makeup.

Third, it is important that information about a diagnosis not be used as a license for a child to engage in unacceptable behavior. For example, a child with autism or Prader-Willi syndrome may be more likely than other children to have tantrums when frustrated. In spite of this disability-related tendency, children should be expected to try to control their behavior. Furthermore, parents and teachers can deal with these tantrums as they would with the tantrums of a child who does not have a disability. This may mean, for example, removing the child to a separate room as soon as he or she begins to scream. Certain ground rules need to be applied universally, regardless of a child's disability.

Finally, it is important to remember that diagnostic labels have the potential to be stignutizing. This recognition has led to many recent changes in the terminology used to describe disabilities. "People-first" language—for example, saying, "a

child with Down syndrome," rather than "a Down syndrome child"—represents an attempt to ensure that the child comes before the label. Diagnostic labels that are especially stigmatizing, such as "mental retardation," are perhaps best used only for specific purposes, such as when parents and teachers are looking up information, but not in everyday conversation about the child.

### Can behaviors that are known to be part of a syndrome be modified through the same intervention approaches that help other children with the same behaviors?

Most behaviors associated with syndromes can be modified to some extent, although the behavior may be more difficult to modify than the same behavior in other children. Here are some steps parents and teachers can take when considering attempts to modify behaviors associated with specific disabilities:

• Consider whether the behavior has a function or purpose for the child. This process, sometimes called "functional analysis," can help parents and teachers determine whether the behavior in question really needs to be modified. At best, some "unusual" behaviors associated with a developmental disability may serve an important function. At the least, the behavior may be harnless. For example, the hand-flapping of a child with autism may help the child express excitement in a way that allows others to respond. This behavior may not need to be altered, at least not until the child learns other ways to express excitement.

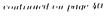
Behaviors that are highly resistant to change often serve a function—as difficult as it is to know exactly what that function might be. For example, some people theorize that the gaze aversion often present in children with fragile X syndrome when they are speaking, may be a strategy they use to better concentrate on their words without being distracted by the visual stimulation of a face.

Even if the behavior seems to have a function for the child, it may be possible to teach other behaviors that have the same function but interfere less with everyday life. For example, a child with autism who screams when the room gets too noisy may be taught to put on headphones instead when excess noise occurs.

- Find ways to reduce stress. When under stress, most people have more difficulty controlling what might be considered "biologically-driven" behaviors. In stressful circumstances, for example, people may eat more, bite their nails or have trouble paying attention. Finding ways to reduce a child's stress and maximize his or her happiness and success can lead to a reduction in many challenging behaviors.
- Establish specific environmental adaptations. Some behaviors associated with a developmental disability can be modified by changes in the environment. For example, the food-seeking behavior of a child with Prader-Willi syndrome can be reduced if food is stored out of sight. And a rocking chair in



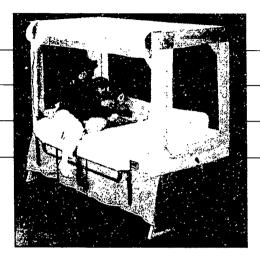
Children with Williams syndrome are often noted for their enthusiastic, outgoing personalities. (Photo courtesy of Williams Syndrome Association)





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continued from page 39

the classroom may provide a socially acceptable outlet for a child with Williams syndrome who has a tendency to "rock" his or her body. Consultation with a behavioral psychologist is often helpful.

• Try techniques of positive behavioral management. This means making sure the challenging behaviors do not receive "rewarding" responses, while other, more desired behaviors do.



Lindsay Williams and David Gammon enjoy playing Nintendo. Lindsay and David live in a specialized group home for individuals with Prader-Willi syndrome. (Photo courtesy of Keystone City Residence, Scranton, PA)

Sometimes parents or teachers are surprised to find they have been inadvertently rewarding a behavior they are trying to modify. For example, a child with autism may flap his hands when he gets excited. In an attempt to stop this behavior, whenever the child flaps his hands, a parent or teacher approaches the child and holds his arms down. Suppose, however, that the child enjoys this attention and closeness; how long before the child learns that handflapping leads to hugs? As a result, the child's hand-flapping behavior may actually increase—the opposite result of that intended by the adults in his environment!

• Medications may be useful. Many biologically-regulated behaviors can be modified through the use of medications, particularly when combined with changes in the child's environment. It is important to respect the legitimate philosophical stance of families who do not wish to use medications with their child. But increasingly, psychotropic medications are being used to influence many of the behavioral challenges associated with specific developmental disabilities.

For example, the skin-picking and other perseverative behaviors associated with Prader-Willi syndrome are often very responsive to a combination of stress-reducing environmental modifications and treatment with medications such as Prozac. The hyperactivity and distractibility often seen in children with Williams syndrome, and in some children with Down syndrome, is usually helped substantially by reducing environmental stimulation, increasing structure, and sometimes by the use of a stimulant medication such as Ritalin. The extreme anxiety of many children with autism may also respond to medication, along with environmental changes such as predictable schedules.

Medication will not help every child. Some children respond to certain medications very successfully; others may show only a mild response or none at all. For some children, a medication may even have the opposite effect of that intended. A child using any medication, especially a relatively new psychotropic medication such as Prozac, must be closely monitored by his or her medical team. At least one member of that team should be an expert in the use of

-continued on page 44

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### **Developmental Syndromes: Impact on Learning and Behavior**

This table provides information regarding behavioral and learning characteristics that tend to be associated with four specific diagnoses—Williams syndrome, Prader-Willi syndrome, Down syndrome and autism.

The table reflects a model for thinking about children's strengths and challenges, but it is important to remember that it is based primarily on the observations of professionals and parents, rather than on the results of conclusive research.

In the table, plus symbols (+, ++, ++++) indicate increases in a specific behavioral or learning characteristic in relationship to a particular diagnosis. For example, "+" indicates a slight increase in the level of a specific characteristic in relation to a particular diagnosis; "++" indicates a significant increase; and "+++" indicates a very significant increase. Minus symbols (-, - -, - - -) indicate decreases. "N.A." indicates that there is no particular relationship between the behavioral or learning characteristic and the specific diagnosis. For example, the table indicates that children with Williams syndrome have very high levels of "sociability," while children with autism have very low levels of this characteristic. The table also indicates that "sociability" is not a characteristic that seems to be affected one way or another by a diagnosis of Prader-Willi syndrome or Down syndrome.

		Diagnosis			
		Williams syndrome	Prader-Willi syndrome	Down syndrome	Autism
1	Sociability	+++	N.A.	N.A.	
	Arousal	+++		-	+
	Anxiety	++	N.A.	N.A.	++
8	Attention span		N.A.	N.A.	+/-*
Behavioral/Learning Characteristics	Perseveration	+	++	N.A.	++
acter	Appetite	•••	+++	+	-
Char	Depression	N.A.	+	N.A.	?
Bull	Spatial analysis		N.A.	N.A.	+++
Lean	Expressive vocabulary	++	+	-	+
ora/	Pragmatic language	+++	+	++	
shavi	Face analysis/memory	+++	N.A.	N.A.	
ă	Hyperacusis	+++	N.A.	N.A.	++
İ	Touch sensitivity	++	N.A.	N.A.	++
	Fine motor ability		N.A.	-	+
	Gross motor ability				+

^{*} Some children with autism appear to have a very short attention span. Many others seem able to attend for very long periods to some activities, while attending only briefly to others.

### **DESCRIPTIONS OF SYNDROMES**

Williams syndrome (WS) is a non-inherited developmental disability caused by a genetic mutation. WS usually results in a variety of developmental differences, often including learning problems, with strengths in language and weaknesses in math and handwriting. Children with WS often have high levels of sociability, musical talent and a short attention span. WS results in a variety of physical differences, including a unique facial appearance, shorter height and an increased risk of heart problems. WS occurs in approximately one in 20,000 individuals.

Prader-Will syndrome (PWS) is a non-inherited developmental disability caused by a genetic mutation. PWS usually results in a variety of developmental differences, usually including learning problems, with strengths in long-term memory and reading, and weaknesses in short-term auditory memory. Individuals with PWS are usually social and nurturing. Physical characteristics usually include a unique facial appearance, shorter stature, heightened appetite and difficulty controlling behavior when upset. PWS occurs in approximately one in 20,000 individuals.

Down syndrome (DS) is a non-inherited developmental disability caused by a genetic mutation. DS results in a variety of developmental differences including learning problems (usually mental retardation) and better receptive than expressive language. Physical characteristics include a unique facial appearance, short stature, low muscle tone and an increased risk of heart problems. DS occurs in approximately one in 500 individuals.

Authem is a behaviorally-diagnosed developmental disability, identified by difficulty in sustaining social Interaction. Children with authem show a diminished use of verbal language and nonverbal communication, including eye contact and gestures. Authem occurs in approximately one in 2.500 individuals.

Sociability: Children who have high levels of sociability often prefer to be interacting with others and may have trouble "tuning out" people to attend to work. Children with low levels of sociability may be difficult to engage or play with, and may make little eye contact.

Arousal: Children with a very high level of arousal may be easily upset, irritable or hypervigilant (easily distracted by the smallest sights and sounds around them). Adults may describe them as "high-strung." Children with a very low level of arousal may appear selepy much of the time, may be slow to respond to external stimulation and may appear sedentary. They may fall asleep easily, even during normal waking hours, if there is a lack of external stimulation.

Anxiety: Children with a high level of anxiety may seem perpetually worried, may become distressed or agitated very easily, and may become especially upset at the anticipation of stressful events. Children with lower levels of anxiety will be more relaxed and will tolerate changes relatively easily.

Attention span: Some children are able to sustain and shift attention as needed for a variety of activities, while others have a very short attention span and trouble staying with activities, even activities they seem to enjoy. Children with short attention spans are often quite easily distracted by other events occurring in the same room.

Perseveration: Children with high levels of perseveration tend to "get stuck on" favorite activities or topics. Children who perseverate may ask the same question over and over, even though they know the answer, or may engage repetitive toy play. Most people perseverate more when under stress.

Appetite: Appetite can be influenced by emotional factors (for example, some people eat more—or less—when depressed), but, to some extent, appetite is also biologically regulated. Some individuals are biologically driven to consume more calories than they can burn up.

Spatial analysis: Spatial analysis means making sense of visual information in which the spatial orientation (for example, left versus right) is crucial. Spatial analysis is involved in such diverse tasks as learning to recognize letters of the alphabet, organizing written work, drawing pictures, assembling puzzles, tying shoes and finding one's way around. Children with better spatial analysis skills are more likely to experience success with these tasks.

Face analysis/memory: To some extent, the ability to remember faces is biologically programmed. Some people are much better naturally at this task than others.

Hyperacusis: This refers to a heightened sensitivity to certain types of sounds, and difficulty "tuning out" background noises. A child with hyperacusis may find certain sounds—such the sounds of vacuum cleaners or ceiling fans—unpleasant. Such children may be disturbed by the humming of an electric clock or water in the pipes, sounds other people may not even notice.

Touch sensitivity: Children with high levels of touch sensitivity may ind certain kinds of seemingly mild touch sensations very unpleasant. To such a child, a tag in the neckline of a shirt may feel like sandpaper. The child may object strenuously to having his hair brushed or cut. He may refuse to wear a hat, or find certain food textures intolerable.

Fine motor ability: This refers to hand coordination and strength. Children with high levels of fine motor ability are more likely to experience success with such tasks as writing, drawing, dressing, tying shoes and manipulating small items like blocks or coins.

Gross motor ability: This refers to coordination and strength of the legs, arms and body. Physical activities that use large muscles activities like walking, running or riding a bike—involve a great deal of gross motor ability.



883



Kaitlin Aubrey Charlton (front) enjoys an afternoon romp with her buddies, Danielle and Allison Regester. Kaitlin, who has Down syndrome, lives in Bel Air, Maryland. (Photo courtesy of the National Down Syndrome Society)

continued from page 40

the medication, and should make other team members and parents aware of possible undesired side effects. It is important to remember that some medications which are helpful at certain doses, can become dangerous (toxic or poisonous) at higher doses.

• Try to help the child make the most of his or her abilities. Some syndrome-related characteristics, such as the low muscle tone associated with Down syndrome, are less modifiable. However, occupational and physical therapies,

along with environmental adaptations, can support a child's ability to use his or her abilities effectively.

Learning what makes a child "tick"

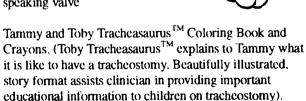
Information about specific disabilities helps parents and teachers understand more about what makes an individual child "tick." This allows these adults to more effectively help the child draw on his or her strengths while overcoming or working around challenges. Parents, teachers, friends, classmates and siblings need to be able to learn about and feel comfortable with behaviors that initially may seem confusing or upsetting. This understanding enables others to more deeply appreciate the child with a disability. And knowledge of the unique strengths and challenges related to a specific diagnosis can be equally invaluable for children with disabilities themselves. EP

Karen Levine, Ph.D., is director of psychology at the University Affiliated Program, Institute for Community Inclusion, Children's Hospital, Boston, Massachusetts. She is also an instructor at Harvard Medical School. Dr. Levine specializes in psychological consultation for children with autism, Williams syndrome and other developmental disabilities, and their families.

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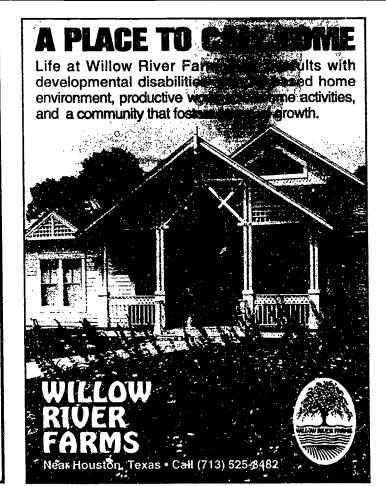
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# Fighting For Our Lives

by Bob Williams



hen many of us joined President Clinton's administration, we did so with a sense of hope and renewed commitment to bettering the lives of children and families. We had reason to be upbeat and optimistic, especially regarding the federal policy outlook for Americans with significant disabilities and their families.

Sadly though, these past 12 months have made a terrible difference. We all know why this has happened, so I will not spend time reviewing the obvious. But collectively, Americans with disabilities and our families are now facing the fight of a lifetime.

### A personal and historical context

I want to put this in a personal, as well as historical context. Like increasing numbers of individuals with significant disabilities, I have beaten the odds society stacks up against us—prejudice, stereotypes and continuing discrimination. I owe my success, first and foremost, to my parents, who refused to accept society's low expectations for the youngest of their five children. Instead, they helped me to set and achieve high expectations.

Bob Williams is Commissioner of the Administration on Developmental Disabilities in the U.S. Department of Health and Human Services, Williams has cerebral palsy and uses augmentative communication.

This article was adapted from a speech Williams gave at the 1995 National Collaborative Academy on Mental Retardation, sponsored by the President's Committee on Mental Retardation.

And, like many others with severe disabilities. I owe at least part of my success to the luck of having been born at an extremely fortunate time in our nation's history. This is critical for today's parents to understand, because some people in our country seem

intent on turning back the clock.

Many of us remember a much different time. In the early 1960s, for example, children with cerebral palsy who drooled, as well as children considered to be mentally retarded, were legally barred from attending most public schools in my home state of Connecticut.

Fortunately, those laws changed. By the mid-sixties when I started school, things had improved. Even so, my first class-room was in a church, not because my parents were particularly religious, but because this was the only place in town that would have us.

A few years later, I asked the special education director of my town why I couldn't go to the same school as my brothers and sisters. His reply was as straightforward as my question; he told me I couldn't go to regular classes because I didn't speak clearly enough.

I never did develop clear speech. But something else changed. As simple technology like electric typewriters, computers and communication devices became more available, expectations increased. Parents became bolder and more organized. As a result, state laws began to change.

Soon, access to a regular school classroom was no longer seen as a privilege but as our right. By 1975, federal law was on the side of millions of students with disabilities who were intent on getting a high-quality education in the maistream.

A few years later when I graduated from high school and wanted to go on to college, federal law was on my side again—this time in the form of the Rehabilitation Act of 1973. When others expected me to go quietly into a sheltered

workshop for the rest of my life, my parents and I had other ideas. And we knew the Rehabilitation Act was one of our strongest tools for pursuing the future we envisioned.

On July 26, 1990, a day of historic promise and opportunity, the Americans with Disabilities Act (ADA) was signed into law. And thanks to President Clinton's effective enforcement of the ADA, we have continued to make significant progress in opening previously-closed doors.

Today, however, we are at a fundamental turning point with respect to the kind of future we can expect for ourselves and the kind of future all of our young people can expect to inherit. "Inclusion-bashing" is becoming more and more popular. Many people are quick to blame inclusion for whatever ails our schools and country, it is placing the blame on those of us who act, think or express themselves differently.

### "Forces of derisiveness and division"

As President Clinton told a group of us who met with him to mark the fifth anniversary of the ADA, the forces of derisiveness and division are all around us, threatening to undermine the civil rights of all Americans, including children and adults with disabilities.

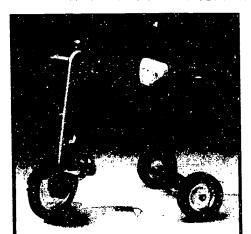
- IDEA: We are facing real challenges to reauthorizing the Individuals with Disabilities Education Act (IDEA). This law enabled nearly two million of us to get a quality public education. Now there are those who want to take this opportunity away.
- ADA: The ADA is also under attack. President Clinton has stated that he will veto any attempt to repeal the law. But he has warned that there will be more subtle, but still potentially damaging attacks aimed at cutting ADA technical assistance and enforcement efforts.
- SSI: Similarly, SSI payments to children with disabilities are under intense scrutiny. Under a House-approved plan, approximately 177,000 children with disabilities would lose all SSI benefits and Medicaid. An additional 613,000 kids would lose SSI benefits while retaining Medicaid eligibility.

While there is no question that the childhood SSI program is in need of restructuring, this can be done without wrecking havoc on the lives of these kids

continued on page 47



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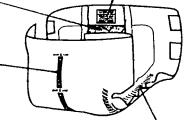
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**EXCEPTIONAL PARENT / OCTOBER 1995

887

and their families. The childhood SSI program has been a big factor in the reduction of admissions of children with mental retardation to state institutions. Today there are still some 4,000 such youngsters in these facilities—4,000 too many. But 30 years ago, there were 98,000 kids in these places. Do we really want to return to those times?

• Medicaid: If you've been thinking this is just a lot of federal gobbledy-gook that doesn't affect you or your family, think again. Chances are that most Americans with significant disabilities will be affected by proposed cuts to the Medicaid program.

Everyone agrees that Medicaid is out of control. The program now costs 88 billion dollars annually; within five years, that cost is expected to reach 150 billion. This is clearly unacceptable. But despite its many flaws, it is important to remember that Medicaid is the major source of day-to-day survival for millions of individuals with significant disabilities. It pays for personal assistance, assistive technology and other support services. Without it, hundreds of thousands of our sons, daughters, brothers and sisters will once again end up lying in their own excrement.

SOME
PEOPLE IN
OUR COUNTRY
SEEM INTENT
ON TURNING
JACK THE
CLOCK.

President Clinton
has proposed several ways to reform
the Medicaid program. His suggested
remedies include
truly comprehensive national health
reform, grants to
help states expand
access to consumer-driven personal assistance
and, most impor-

tantly, the elimination of the federal deficit—not in seven years—but over a 10-year cycle so needed cuts can be made more gradually, at far less human expense and with much more forethought.

Tragically, the Republican leadership in Congress has rejected every one of these thoughtful proposals.

Instead, Medicaid cuts proposed by Republicans would force states to slash services. The first to go would be services such as personal assistance and assistive technology. And this is just the beginning. By 2002, these Medicaid cuts would eliminate coverage for nearly nine million children, elderly people and individuals with disabilities.

### Fighting for the future

What would these cuts really mean? A few weekends ago, someone asked me this very question. The questioner was a contemporary of mine, a woman with very significant physical disabilities who relies on augmentative communication like I do.

There was no sidestepping or sweetcoating the issue. I gave her the only honest and direct answer I could: These cuts, along with the power of the nursing home lobby, would mean that thousands of people with disabilities would be forced into nursing homes once again.

If there is one message I want you to take away, it is this: You and I are fighting for our lives, for our future and for the right to decide that future for ourselves. But most of all, we are fighting for the lives, the futures and the fundamental civil rights of our sons and daughters. **EP** 





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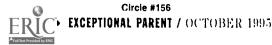
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# Networking

### **Information from The National Parent Network on Disabilities**

### The National **Parent Network** on Disabilities **Board of Directors**

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Advocates for Children of New York. Long Island, NY

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Disability Rights Education & Defense Fund (DREDF). Berkeley, CA, Vice President

### **Janet Vohs**

Federation for Children with Special Needs, Boston, MA, Secretary

### Patricia McGill Smith Executive Director

#### Correction:

The Nevada Parent Training and Information Center (FTI) was listed incorrectly in the August issue of Networking. The correct listing is:

#### Nevada PEP

(Parents Encouraging Parents) 4970 Arville St., Ste. 110 Las Vegas, NV 89118 (702) 253-1939 "72) 367-9812 (fax)

# **IDEA Reauthorization Update**

As Exceptional Parent was going to press, it became clear that the House of Representatives intended to consider and rewrite the reauthorization of the Individuals with Disabilities Act (IDEA) by the end of September. This makes House floor actionincluding debate, amendments and a vote on the reauthorization—likely to occur during October. The Senate is expected to make its version of the bill public no later than September 25, with deliberation, rewriting and possibly a vote before the end of October. Our children's access to public education will be decided within the next few weeks.

This installment of Networking will examine the proposed changes to the IDEA and their impact upon children and youth with disabilities. As it appears now, both the House and Senate versions of the IDEA would seriously erode the due process rights of children with disabilities. Call or write to members of your congressional delegation. You don't have to be an expert on the proposed legislation; you are an expert in the day-to-day real world. Your legislator may never have met a special education student. Share your expertise with Congress.

We must act now or we will have no right to complain about what we get. It is not too late to be heard, but whatever you decide to do, do it now!

### VITAL ISSUES

 Students' due process rights would be croded in the guise of discipline. Both the House and the Senate are proposing that students who bring "weapons" to school or behave in a way that is "potentially dangerous to themselves or others" be subject to an "interim, alternative placement." This language would allow a teacher or administrator to unilaterally decide that a student's behavior is "potentially dangerous," thus initiating a process parents could not stop. Immediately, the student in question would be put out of school for 45 days. During that time, a "team" (the IEP team, we hope; but the proposal is vague on this point) would review the student's behavior and overall performance and develop recommendations for his or her next educational placement.

If parents disagreed with those recommendations, they could trigger currently-existing due process procedural safeguards, which are designed to protect parents' right to participate in decisions about their children's education. (Due process begins with legally-established "administrative remedies." The first of these is an "impartial hearing," which concludes with the written decision of the hearing officer. That decision may be appealed, but if that appeal fails, "administrative remedies" have been exhausted and parents must urn to the courts.)

In the situation described above, a student

removed to an "interim alternative placement" would remain there while due process ran its course. However, because in many instances the "interim alternative placement" would be homeschooling, these due process procedures could serve to keep our children at home—just as they were kept at home prior to 1975, when PL 94-142 was first passed. (PL94-142 was the original special education law and the basis of what is now known as the IDEA.)

· Parents would be constrained in their ability to recoup legal fees, even if they win in court. Currently, if parents do not agree with the educational placement of their child, and can't get the situation resolved through administrative remedies, they can take the case to court. If in court, the judge rules in the parents' favor, the school district is required to reimburse them for their legal fees.

The House proposal would add restrictions to the reimbursement of parents' legal fees. For instance, if parents did not notify school districts 10 days prior to filing in court to contest educational placement, legal fees would not be reimbursed. The proposal would also allow the court to reduce fees if the judge determines those fees are higher than "prevailing rates," thus reducing the amount of money parents would be reimbursed, but not the amount of money they would pay. The court could also disallow reimbursement if the parents did not demonstrate "good will" in settling the matter before going to court. However, school districts would not be required to demonstrate that they acted in good faith or seriously attempted to resolve the dispute prior to going to court.

These proposed restrictions on reimbursement of legal fees would make it harder for parents to secure legal representation. Parents can't hire a lawyer if they can't pay for one, and for many parents, it would be difficult to pay a lawyer if those fees weren't reimbursed. The delicate balance of power that now exists between schools and parents would be tilted in favor of schools.

 School districts would be allowed to factor in cost when determining placement. Proposed language would allow school districts to factor in cost when determining placement for special education students; this is not allowed under current law. This could mean that special education students would receive the cheapest—not the most appropriate-services. School districts could reduce their budgets for special education and justify inappropriate placements on the basis of cost.

### HOUSE PLANS TO APPEND IDEA TO THE EDUCATION REFORM BLOCK GRANT

NPND has also learned that the House Economic and Education Opportunities Committee intends to

continued on page 50.

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OCTOBER 1995 / EXCEPTIONAL PARENT . 49

continued from page 49

append amendments of the IDEA to the House version of education reform—the Education Reform Block Grant, It is common practice to modify one piece of legislation by appending amendments onto another piece of legislation. Tying an amendment to a larger bill that is sure to pass assures that the amendment also will pass. For instance, appropriations (budget) bills often include amendments that have nothing to do with appropriations. Those amendments pass,

however, because defeating the amendments would require voting against the entire appropriations bill.

With the IDEA, the House majority has reversed the strategy. They are attempting to gain passage of their version of education reform by attaching the IDEA reauthorizing amendments to it. The assumption is that the IDEA reauthorization is sure to pass, thereby pulling education reform along with it. House staffers have made it

clear that they are pursuing this strategy in order to force the Senate into negotiations on education reform. If the IDEA were not attached to the Education Reform Block Grant, the Senate could pass the IDEA while avoiding education reform. This strategy in no way strengthens the IDEA's content, nor does it increase the likelihood

NPND opposes holding the IDEA hostage to a bill that is controversial, and has forwarded a letter to this effect to the House Economic and Education Opportunities Committee staff. We do not think that this reverse strategy will necessarily work. Usually, amendments added to unrelated bills are minor adjustments. These IDEA amendments are not minor. These amendments fully embody the reauthorized law governing our children's right to a free,

appropriate education.

By the time this article is published, it is likely that the House will have already acted on the IDEA. The bill will be going to the Senate Labor and Human Resources Committee. Contact the senators on this committee immediately, and tell them to reject any legislation that includes the IDEA reauthorization amendments. Committee chair is Nancy Kassebaum (R-KS); members are Spencer Abraham (R-MI), John Ashcroft (R-MO), Dan Coats, (R-IN) Mike DeWine (R-OH), Christopher J. Dodd (D-CT), Bill Frist (R-TN), Judd Gregg (R-NH), Slade Gorton R-WA), Tom Harkin (R-IA), Jim M. Jeffords (R-VT), Edward M. Kennedy (D-MA), Barbara A. Mikulski (D-MD), Claiborne Pell (D-RI), Paul Simon (D-IL) and Paul Wellstone (D-MN).

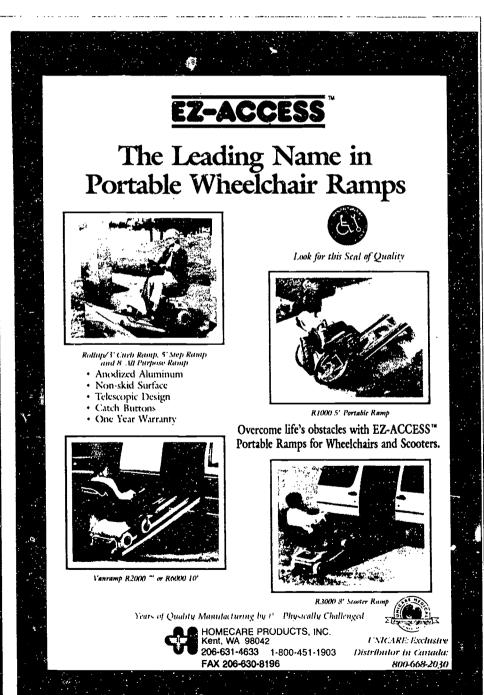
### How to stay informed

The IDEA reauthorization is moving quirkly. The bill's language and issues are changing daily. To be sure you have the most current information, contact your local Parent Training and Information Center (PTT). If you do not know how to reach that center. call NPND (703/684-6763). We'll connect you with informed purents in your state.

### How to communicate your views

Parents are busy people. Yet the need to make our voices heard on these issues is critical, and the time is now! Due to the likelihood that the House will have acted by the time this piece is published, parents should concentrate communication efforts on their Senators. All members of the U.S. Senate can be reached by calling 202-224-3121 or writing to The Honorable Senator , c/o The U.S. Senate, Washington. DC 20510. We must make them hear us!

of quick and easy passage.



CENTER FOR CHILDREN WITH CHRONIC ILLNESS AND DISABILITY

# Children's Health Notes

Resident Training:

### **Pediatricians Make House Calls**

Today, families provide most of the care for children with chronic illness and disabilities and they provide that care at home. Pediatricians can play a major role in teaching families how to care for their child's special health care needs, along with their "normal" developmental needs.

That's why pediatric residents at the University of Minnesota are learning about the chronic needs of children with disabilities from

families. The classroom is the home and community.

The complex and long-term nature of chronic conditions typically require the involvement of a variety of family and community resources. While physicians see these children in the clinic and in the hospital, more often than not it is the families who negotiate their child's daily health and medical, educational and human service needs.

Two pediatricians at a time in their second year of a three-year residency spend four weeks in a neuro-developmental disabilities rotation learning about children with chronic illness and disabilities, and the impact of these conditions on the families who care for these children. Their time is divided among

a variety of activities: home visits, community visits, in-patient and outpatient clinical care, and classroom discussion.

Resident Training
Turn to page 52

The Center for Children with Chronic Illness and Disability is learning a great deal about children with chronic illness and disabilities, their families, and the political, health care, and policy environments that affect their care. To reach as many families as we can, we join with Exceptional Parent to publish Children's Health Notes to define the environment, raise questions, identify strategies, or provide clarification of issues that are critical to providing care for children with special needs and their families.

**DEFINITION** 

### Resident

A postgraduate physician receiving training in specialized areas such as pediatrics, family medicine, internal medicine, or surgery.





### Children's Health Notes

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PRODUCTION/ **EDITORIAL ASSISTANT** Linda Pra::

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Children's Health Notes Box 721 420 Delaware St. SE Minneapolis, MN 55455 (612) 626-4032 V (612) 624-3939 TTY

Resident Training From page 51

### Home Visits:

The Parents-As-Teachers program allows residents to learn more about the daily challenges facing children with chronic conditions and how to coordinate care with families. Residents encounter a variety of experiences. A resident may attend the child's school, go out for dinner or go bowling with the family, or may learn about elaborate home medication regimens.

Before visiting with the families, residents view a videotape prepared by a group of parents. Family members describe interactions with

physicians,

system and

experiences with

the health care

the impact of these factors on their lives.

- One family shows slides of activities at home which provide a rare glimpse into the life of a family who works endlessly to provide "normalizing" experiences for its children.
- One parent tells how she cringes when her deaf child is labeled handicapped or crippled.
- Another parent asks a physician, "How will you know when a parent is overstressed? What will you do about it?"

The videotape and the guided discussions that follow provide the background for home visits.

One resident says his family visit reminded him that parents with children who have disabilities are parents first. "Along with managing all those medications and adapting their lifestyle to accommodate their needs, they still cook the hot dogs, keep the kids from fighting, and do what all parents must do."

He goes on to say, "The children with special needs are children who need attention, direction and love "

Another resident recognized parents struggling with tough questions like, "What are the limits of my son's potential. How far do you push?" Most often, residents express how impressed they are with the family's resilience.

Like the residents, families often gain insights. One mother of a daughter with cerebral palsy writes: "I think it's a great program. I think the residents who participate in this will be better prepared than the current medical professionals who didn't have this opportunity and are uncomfortable with the disability or loss. Another mother reported that she would like to see the program expanded to include other experienced medical people, teachers, physical therapists, occupational therapists

> Resident Training Turn to page 53



Resident Training From page 52

and other professionals with whom families work.

### Community Visits:

Collaborating with families often involves coordinating care with community resources. Each month, the residents visit two fully integrated community sites in collaboration with the University of Minnesota's Institute on Community Integration. Ten community agencies, including early intervention and elementary school sites, community employment agencies and community recreation sites. participate. Residents learn about linking families with needed resources and coordinating care more effectively with the family, the health care system and community agencies.

These visits provide residents with a sense of the variety of resources available to children with special needs.

"What an eyeopening experience," one
resident explained. Prior
to this experience, few
residents knew the extent
to which children with
disabling conditions
could be included within
the community and the
school. One group of
residents was struck by
the range of physical
development of the
children in one school
room but they were even

more amazed by the wide range of functional abilities represented.

During the summer months, residents see kids at camp. Two physicians recall watching a child precariously being transferred from boat to wheelchair.

"All the kids came running out of the unstable boat and here was this counselor trying to keep his balance and get out while carrying a camper," Dr. Joseph-DiCaprio said. A mom herself, she wondered, "What would happen if the child fell in?" The question answered itself: What would happen if any of the children fell in?

"Maybe we are the ones who are afraid."

Rather than focus on what is wrong with a child and what can go wrong, as they must in order to understand the child's medical needs, residents are asked, "How can we strengthen this child's capacities?" This rotation allows the time for residents to discuss the roles they can play in the lives of children with disabilities and their families.

### Clinical Encounters:

The rotation is based at Gillette Children's Hospital, a regional health center in St. Paul for children and adolescents who have disabilities. A total of 24 residents per year attend daily in-patient rounds and care for children

with chronic illness or disability who are hospitalized, and children and families in a variety of clinical sites.

### Classroom Discussions:

Discussions are led by facilitators who provide care for children with chronic conditions and who come from a variety of backgrounds, including medicine, nursing, social work, and psychology. Each facilitator meets with the residents to discuss key issues such as coordinating care with families and teaching them to manage chronic conditions.

Residents meet with a family psychologist to discuss how they can assess and promote healthy functioning in families. The facilitator who works with adolescents and parents in the community leads a discussion about normal developmental issues facing families during adolescence. The emphasis is on how physicians can promote healthy development in adolescents with chronic illnesses and disabilities during this time.

During the orientation to the community, residents are engaged in discussions about the function, organization, and role of interagency collaboration of the major community systems of support: health, education, human and social services. Residents then meet for a

second seminar to discuss experiences and share their observations. They learn the differences between system-centered programs (like hospitals) and family-centered programs, and are shown that most often success really requires an interdisciplinary and interagency team.

On the last day of the rotation, residents discuss their experiences

Resident Training
Turn to page 54

The intent of the Parents-As-Teachers program is to provide the trainee a realistic view of life and issues outside of the clinic setting.

- 1. How does the family incorporate a child with a disabling condition into their regular routine?
- 2. How does the family create a positive environment for the child as well as for the rest of the family?
- 3. What are the special skills and competencies that a family develops in managing the often complicated care of their child?
- 4. What services and service providers are truly supportive of the family?



6.50

If you want to learn more about the Parents-As-Teachers program, contact:

Peter A. Blasco, M.D. Associate Professor Director, Developmental Disabilities Rotation Box 721 UMHC 420 Delaware St. S.E. Minneapolis, MN 55455 612/626-2401

01

Harriet Kohen, M.A. Coordinator, C3ID Box 721 UMHC 420 Delaware St. S.E. Minneapolis, MN 55455 612/626-4032

or

Celia Shapland, R.N., M.S.N., PACER Center 4826 Chicago Ave. So. Minneapolis, MN 55417 612/827-2966

Resident Training From page 53

in the Parents-As-Teachers program with the director of the disabilities rotation, Dr. Peter Blasco, M.D., and with the families they visited. Ordinarily, one parent from each family attends. The goal of this session is for residents and parents to communicate comfortably and openly with each other as they share the insights they have gained through the program.

# **Building A Parents-As-Teachers Program In Your Community**

Developing a Parents-As-Teachers program takes both patience and collaboration.

One of the developers of the program, Dr. Barbara Staub, a pediatrician, remembers answering an ad in a PACER newsletter in the fall of 1988. As the parent of a child with disabilities, Staub was interested in joining a group of parents and health professionals in a discussion of how they can better communicate with health care providers.

The group finally met in the fall of 1989. "We all agreed that doctors could do a better job of communicating with parents," Staub says. And after many phone calls and meetings, she and her Collaboration Among

Parents and
Professionals (CAPP)
colleagues went on the
road, making
presentations to
physicians and health
professionals at Maternal
and Child Health
conferences and
continuing medical
education programs.

By August, 1990, "Parents-As Teachers" had found a temporary home in the adolescent health training rotation at the University of Minnesota after two successful years. The program was permanently incorporated in the developmental disabilities rotation.

If you are interested in replicating this program, keep in mind that the curriculum for both medical students and pediatric residents is crowded. Try to link up with a sympathetic physician and committed parent group. Together, you'll need:

1. A designated time when the trainee (medical student or resident) is focused on chronic illness.

- 2. A program director committed to organizing and coordinating the experience and incorporating it into related clinic and didactic activities.
- 3. A parent group committed to expending the time and energy to recruit and help organize participating families.

### The Center for Children with Chronic Illness and Disability

was established in October, 1989, and is housed at the University of Minnesota. The organization is a research and training center dedicated to the study and promotion of psychological and social well-being of children with chronic conditions and their families.



## MEDIA

PARENT SURVIVAL MANUAL

PARENT SURVIVAL MANUAL: A GUIDE TO
CRISIS RESOLUTION IN AUTISM AND RELATED
DEVELOPMENTAL DISORDERS, edited by Eric
Schopler, includes many practical suggestions
for dealing with the day-to-day challenges of

life with a child who has autism. The book was developed as a result of collaboration between parents and professionals, and is available from EXCEPTIONAL PARENT LIBRARY (800/535-1910). The following is an excerpt from Chapter 4: "Play and Leisure."

**Changing the Game For Success** 

Children or adults with developmental disabilities may not enjoy particular activities because they are not successful at them. Sometimes, changing the equipment, the rules or the order in which the activities are done can make a dramatic difference in the individual's enjoyment.

Melissa has some physical coordination problems in addition to her autism. I was pleased that she was going to the bowling alley with a group of young adults. I thought the exercise as well as the company would be good for her. However, she found the bowling so confusing and difficult and did so badly that she started flapping and whooping until everyone in the place was staring. The next time they went, someone brought a three-foot-long aluminum ball chute that was set up at the line. Melissa didn't have to measure out her steps and swing the ball back, which was difficult for her. She just set it on the chute and pushed. It rolled and knocked down rows of pins to the shouts and cheers of her group. Melissa was the high scorer for the night. Now she looks forward to bowling, and the only gestures she has are "high fives" with a buddy when she bowls the pins over.

No one likes an activity in which there is no chance of success. A considerate person in the bowling group adapted the skill level needed to accommodate Melissa's limitations. She was then free to enjoy the success of bowling and the supportive company of her cheering peers. Here is another example of adapting equipment:

Our son, Danny, 5, does not like a traditional swing because his feet don't touch the ground when he is in it. He can't move the swing by himself, and feels uncomfortable when someone is pushing him and he can't stop the swing himself. So we hung a tire swing that he can lay across and propel with his feet still on the ground. He loves it!

Swinging was frightening for Danny because he was not in control of making the swing move or stop. After his parents adapted the swing, Danny enjoyed swinging more because his feet touched the ground and he was in control of the swing. He could also be more independent. Parents

have always modified game rules for younger family members by moving the child closer to a throwing target such as a basketball hoop, a beanbag target or a dart board.

Sometimes, even individualized rule changes are helpful in adjusting an activity.

My son, Dwight, really wanted to play softball with his older brother, Mike, but he couldn't throw or catch well enough, and he could never hit the ball with the bat. He would fuss and whine when the kin's wouldn't let him play. One day, Mike told Dwight that if he didn't talk to or touch the runner, he could run to the first-base coaching box every time there was a hit. Now when the older kids get a hit, he races along outside the baseline to the coach's box. He's really picking up speed, and the kids don't mind having him around now that he doesn't whine. They even practice playing catch with him now, so it won't be too long until he'll really be able to play ball (or join a running team) with kids his own age.

This brother was patient enough to find a way to involve Dwight in the baseball game and make it more enjoyable for both of them. Other rule adjustments that parents and teachers suggest include having everyone on the side get a turn at bat instead of retiring the side after the customary three outs. Table games and other less active games can also be adapted so that they are easier to take part in, but still enjoyable for everyone who wants to participate.

Bob, our 10-year-old autistic son, is the youngest of three closely aged children. The two older siblings often involve him in their games and activities by changing the rules or leaving out the parts that are too difficult for him. For example, in the commercial game "Sorry," a move can be spill between two tokens—the number 7 can be completed by moving one token 3 spaces and another token 4. When Bob is playing, everyone completes his or her move with one token only. This is less confusing for Bob and makes game time more fun.

This family adapted a game for their son by changing the rules to fit Bob's way of learning and understanding. To eliminate confusion, everyone who was involved in the game used the same rules. The more concrete the rules are, the better an autistic person will be able to participate. **EP** 

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Coming in November...

An excerpt from Medical & Surgical Care FOR Children with Down Syndrome: A Guide FOR Parents. Written by 25 leading medical experts, this new book provides in-depth, easy-to-understand information on specific conditions that are common among children and adults with Down syndrome. This book is available from Exceptional Parent Library (800/535-1910).





# HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

### **Health Insurance for Federal Employees**

Plan maximums and "medical necessity"

My children and I are covered through a health insurance plan for federal employees. All of my children have pervasive developmental disorder (PDD) with autistic traits. They need ongoing physical, occupational and speech therapy. The insurance company has paid for these services in the past, but now they are balking. I've enclosed insurance company statements and copies of the correspondence between the insurance company and myself. Can you help?

Your health insurance plan is a benefit plan sponsored by an association of federal employees rather than a traditional insurance policy. This means the plan is regulated under a law called the "Federal Employees Health Benefits Act," which establishes specific rules for claim appeals.

I've reviewed each Explanation of Benefits Statement (EOBS) you sent. Many of these claim denials are based on the grounds that the treatment "...exceeds the maximum allowed by the plan."

A representative of your plan told me that its rules regarding physical, speech and occupational therapy changed last year. Although plan participants apparently were notified of

the change, you may not have realized its effects.

At this point, your benefit plan allows a maximum of 50 visits a year for physical therapy and a maximum of 30 visits a year for speech and occupational therapy combined. Any further treatments would be denied, and the explanation on the EOBS would probably be: "...exceeds the maximum allowed by your plan."

If you have not exceeded the plan maximum, you can appeal the claim denials on that basis. If you have exceeded the plan maximum, however, I doubt a claim appeal will be successful.

Many of your other claim denials are based on the grounds that the services "... are not covered expenses under the plan." That phrase has to do with the plan's definition of "medical necessity." It's important to understand that the plan isn't using the term "medically necessary" in an absolute sense; rather, it is working from its own definition.

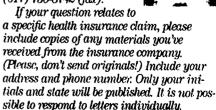
Under that definition, your policy covers, for example, speech therapy "...to restore attained functional speech [lost] due to illness or injury," but not therapy "...directed at improving existing speech and addressing speech delay."

> On that basis, the benefit plan has concluded that your children's "...occupational, physical and speech therapy would not be medically necessary."

Your first step should be to review the denied claims, and the reasons for those denials, with a benefit plan representative. It's a good idea to have the EOBS in question with you during that phone conversation.

If that discussion does not lead to resolution, you can file an appeal. The "Federal Employees Health Benefits

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146. (617) 730-8742 (fax).



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Act" provides that appeals can be made only to the U.S. Office of Personnel Management. However, the maximum number of visits for speech, occupational and physical therapy and the benefit plan's definition of "medical necessity" are unlikely to change as the result of an appeal. (You can, of course, discuss these issues with an attorney.)

However, if your children are currently in school, and their participation in speech, occupational or physical therapy can be linked to possible progress in educational activities, such therapies can be specified in the children's Individual Education Plans (IEPs). School districts are legally obligated to provide all services listed on the IEP.

Many federal employees can choose from a variety of health insurance plans. Given the situation, it's important that you to begin to review the benefits offered by other available insurance plans before the next "open enrollment period." This period runs from the Monday of the second full work week in November through the Friday of the second full work week in December, or as otherwise announced by the U.S. Office of Personnel Management. Be sure to ask specifically about the insurer's definition of "medically necessity" in relation to speech therapy, and about specific limits to the yearly number of speech, occupational and physical therapy sessions. **EP** 







### **GALAXY GROWTH CHAIR**

The Galaxy Growth Chair is an expandable, adjustable wheelchair designed for children weighing between 25 and 110 pounds. This chair adjusts from 10 to 16 inches wide, can be used as a push

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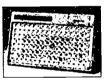


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The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on Exceptional Parent's "Free Product & Information Card," Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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CHAIRSCHOLARS FOUNDATION, INC43	¹ 98	KIO-KART/KID CARE	14
11 CHILDREN'S SPECIALIZED HOSPITAL	133	KIMBERLY-CLARK	
146 CHRYSLER CORPORATION	45	LAUREATE LEARNING	
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150 COLUMBIA MEDICAL	139	NR LABS, INC	
126.208. 209. 210 CONVAID	1	OPPENHEIM TOY PORTFOLIO	
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	25   226   727   728   729   730   731   732   733   739   230   230   237   230   239   249   751   751   752   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   753   7
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# ASK THE DOCTOR

by David Hirsch, M.D.

## **Unexplained Health Problems**

Our son is now seven years old. Our son is now seven years out. He was born at 29 weeks gestation and had a complicated neonatal course. As a result of his prematurity and respiratory problems, he developed a grade IV interventricular hemorrhage (IVH), a bleeding into one or more of the small brain cavities that are necessary for the production and circulation of spinal fluid. Subsequent to this, he developed hydrocephalus (accumulation of the spinal fluid in one or more of the ventricles, causing expansion of the ventricle which results in excess pressure in the brain), cerebral palsy, epilepsy and optic atrophy (degeneration of the nerve to the eye, responsible for sight). He needs some help with feeding but does not have problems with choking.

For the first five years of his life, he was relatively healthy in spite of his disabilities. His seizures, too, were under good control.

In the last two years, however, he has had more seizures and frequent illnesses the doctors say are "viral," but from which he recovers very slowly. In fact, he seems to be sick more than he is well. He has had recent problems with constipation, too; this is also something new.

His doctor did a number of blood tests, including tests of his immune system. All the results were normal. X-rays of his chest and sinuses were also normal.

I am worried that these frequent illnesses will stress my son's heart and lungs. His doctors tell me it is normal for children with his type of chronic

In this column, David Hirsch, M.D., a pediatrician and member of the EXCEPTONAL PURENT'S Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with

developmental disabilities and chronic illnesses.
Since Dr. Hirsch has not examined the
child in question, parents need to review his
suggestions with appropriate professionals.
Mentions of specific products or medications
illustrates suggestions; he is not endorsing
any specific products.

Send questions to: Ask the Doctor, EXCEPT-IONAL PUBNIT, 200 Harvard Street, Suite 903, ine, MA 02146-5005, (617) 730-8742 (Fux). medical problems to have unexplained health problems. What do you think? Have my son's doctors looked far enough to find a cause for his problems?

Children like your son, who have chronic medical problems, can be relatively healthy for many years. Unless there is an underlying heart or lung condition you did not mention, your son's illnesses should not cause heart or lung problems—unless he develops serious lung infections in the years to come. I wish I knew more about the specific type of infections your son has had. For example, were they just frequent colds or were they infections of a more serious nature, such as recurrent sinus infections, bronchitis or pneumonia? Without that information, it is hard to know whether the doctors ran sufficient tests to rule out any serious immune problems.

Did the doctors give you a reason for your son's increased number of seizures? Because he has hydrocephalus, I am assuming he has a shunt. Is the shunt working properly? His frequent viral infections might be responsible for the increased seizure activity, but other reasons such as inadequate medication or worsening of his hydrocephalus should be ruled out first.

Constipation is common in individuals with cerebral palsy because of lack of activity and an inability to bear down properly to have a bowel movement. This tendency to constipation may become a more serious problem if inadequate fluids are taken in because of the nausea, vomiting or fever that may accompany recurrent infections such as your son's.

It is hard to say when your son's condition will improve. But make sure he is getting a diet that supplies him with all the calories, nutrients and fluids he needs. Continue to work with his primary physician, who would be best able to coordinate the evaluations of any other doctors (specialists) involved in his care. Do not hesitate to ask questions and make the doctors aware of your concerns. **EP** 

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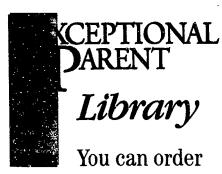
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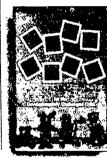
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ranges for 75 commercially-available toys that are especially appropriate for children with visual impairments. The 1995–96 edition features a greater selection of toys in a wider price range, including many lower-priced products; it also features a new category, "Books and Fun Skills." To receive single or multiple free copies of the *Guide*, send a postcard to Toy Manufacturers of America, 200 Fifth Avenue, Suite 740, New York, NY 10010. The postcard should say that you want the *Guide* and should specify the number of copies requested.

• The USA Toy Library Association (USA-TLA), a national network of toy lending libraries, serves children with and without disabilities. Depending on the particular program, families may borrow both commercially-available and specially-adapted toys. Both options may be helpful to families of children with disabilities; before purchasing, parents can determine whether their child enjoys and can use a particular toy.

USA-TLA helps people establish and promote toy libraries in local communities; distributes information on toy repair and discounts; provides research material on play, toys and early learning; and offers books. videos and a quarterly newsletter.

Some toy libraries charge a nominal membership fee. For more information, or to locate the toy library nearest to your home, write to USA-TLA, 2530 Crawford Ave., Suite 111, Evanston, IL 60201.

• Lekotek Centers, located nationwide, provide direct services, support and information to children with disabilities and heir families. Primary



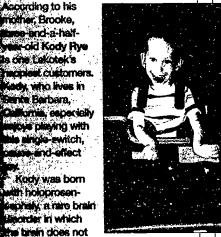
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services include play sessions, focused on facilitating family interaction through play; toy lending libraries, filled with toys adapted to meet the special needs of children with disabilities; and the Compuplay program (available only at some Lekotek centers), which offers individualized computer training and playtimes with adaptive technology as needed. Many Lekotek programs are offered on a sliding-fee scale, with scholarships often available. For Lekotek centers that do not offer sliding fees, yearly memberships cost \$50–180. Compuplay sessions are available at additional cost. For more information on Lekotek, call (800) 366-7529, voice.

• The Lekotek Toy Resource Helpline is a free service offering individualized assistance in selecting appropriate toys and play materials for children with disabilities. This service may be especially helpful for friends and relatives hoping to select appropriate holiday gifts for children with disabilities. From 9 a.m. to 4 p.m. (central time), individuals can reach the helpline by calling (800) 366-7529, voice.

## House Establishes Disabilities Task Force

House Speaker Newt Gingrich (R-GA) has announced the formation of a House of Representatives Task Force on Disabilities. Gingrich appointed six House members to the task force: Bill Goodling (R-PA), Steve Gunderson (R-WI), Sue Myrick (R-NC), Jim McCrery (R-LA), John Porter (R-IL) and Mike Castle (R-DE). Also appointed was Andy Fleming, president and CEO of Paralympics and a constituent in Gingrich's home district.

The task force will coordinate legislative activities affecting individuals with disabilities to ensure that funds are directed appropriately and used in the most cost-effective manner. The task force is developing an out-reach and communication strategy to gather feedback from constituents and to build successful community partnerships.

Gingrich stated, "With the help of this task force, I believe we can channel more assistance to those who truly need the aid, and less to government bureaucrats and those who are not truly disabled. The members will focus on removing disincentives to working, using innovative technologies to provide greater independence for persons with disabilities and increasing opportunities for the disabled to live and work in the community."

Gingrich is also launching a Task Force on Severe Disabilities in his home district, Georgia's Sixth. Eight of the 15 members of that group are individuals with disabilities or parents of children with disabilities. Gingrich adds, "Finding ways to help people with disabilities to become productive, working members of the community is not only good economics, but is morally right."

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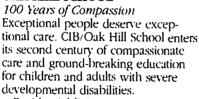
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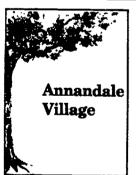
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## **Respecting Dreams... Building Futures**

Autism Society of Obio Annual Conference

November 3 & 4, 1995

The Autism Society of Ohio, in collaboration with the Autism Society of Indiana is pleased to announce the 1995 Annual Conference held Friday and Saturday, November 3 and 4, 1995. This year the conference will be held in Columbus, Ohio at the Columbus Marriot North.

Invited speakers for this conference include: Dr. Ralph Maurer—University of Florida, Dr. Diane Twachtman, Carol Gray, Richard Simpson—editor of <u>rocus on Autistic Behavior</u>, Nancy Dalrymple—University of Kentucky, Dr. Melvin Kaplan—Optical Therapy, Dan Crimmons, Denise Sawan Caruso—SLP/CCC, Lynette Scotese-Wojtila—OTR/L, Sean Barron, Dr. Max Wiznitzer—Rainbow Babies and Children's Hospital, and many more.

The format for the conference will be a keynote followed by breakout sessions. Individual sessions, as well as panel discussions, will be presented.

Professional Credits Pending: Ohio Department of Education Approved Provider, CEU Credit, Ohio Department of MR/DD Credit, Social Work Credit, Nursing, CNE.

For registration forms or more information, call: (216) 655-2568, (216) 467-9491, or (216) 650-1311



On the day of his first big karate tournament. Barry pauses to flash a smile for the camera. With him are two of his biggest fans-David Lloyd, his instructor, and Clara Mills, his grandmother.

Barry, who is very proud of a new earring that makes him "look like a real rock-and-roll star," is a big fan of Elvis Presley. "I'm learning how to play the guitar like the King!" he says.

# CHILDREN'S PAGE

# The **Karate Kid**

by Barry Atkinson

y name is Barry. When I grow up, I will be a black belt in karate. I have taken karate lessons for almost a year. I wanted to take karate lessons because I like Kung Fu movies and because I wanted to know how to

protect myself.

I am an orange belt now. I take karate lessons two times a week. Sometimes I have group classes, and sometimes, I have private lessons. My teacher's name is David Lloyd.

I have spina bifida, which means I don't walk so great. When I first started lessons, I did karate in my wheelchair. But Dave said he wanted me to try to get out of my wheelchair. So I did. Now I do karate standing up like the other kids. Dave says I can do anything I want to do—even if I use crutches and have a trach. He makes me work hard, sometimes until I am sweating! I am the only kid at my studio who uses a walker. Dave doesn't care though; he even makes me do push-ups like the other kids.

Last spring, I was in my first big karate tournament. My grandma came to watch. I was the only kid with a disability, so I was kind of nervous. But I

competed anyway, and I even won a trophy! Dave said he

was proud of me. And I was proud of Dave for being my teacher. EP

> Barry Atkinson, 11, lives with his foster family in Huntington Beach, California. He is a fifth-grader at Moffett Elementary School.



## Parents' turn:

Our 11-year-old foster son, Barry, is a delightful child, who happens to have spina bifida with the Arnold-Chiari malformation of the brainstem and cerebellum, hydrocephalus, a gastrostomy-button and a tracheostomy. Barry spent his first seven years at a state facility for individuals with developmental disabilities, where he was often ill. Many people saw him as a sickly child who was too medically fragile to leave the hospital setting, let alone attempt any kind of sport.

But almost from the day Barry moved in with our family, he begged us to sign him up for karate lessons. We decided to give it a try, but were initially unable to find a studio that would consider accepting Barry. Though discouraged, we kept looking because Barry was so insistent. Finally, we found David Lloyd, a teacher at United Studios of Self-Defense, who was able to look beyond Barry's disabilities. Barry was welcomed with open arms from the first day of class.

Dave has never allowed Barry's disabilities to interfere with his training in karate. To help Barry keep up with his oeers, Dave provides him with extra support and training in weekly private lessons. Dave pushes Barry to do all he is capable of, but also finds creative ways to adapt for Barry's physical limitations.

As Barry's strength and endurance have increased, he's moved from his wheelchair to a reverse walker and, finally, to forearm crutches. He hasn't missed one karate class yet due to illness! It has also been great to see Barry develop friendships with other students; he spends the first few minutes of each class greeting all his friends. Finally, and most importantly, we have seen huge leaps in Barry's self-esteem and confidence. We can't express how pleased we are with Dave and everyone at United Studios. They have made a tremendous difference in Barry's life!

-Mark Andrews & Ann Belles

he Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: Children's Page, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005. S03

68 • EXCEPTIONAL PARENT / OCTOBER 1995

## **General Motors.**



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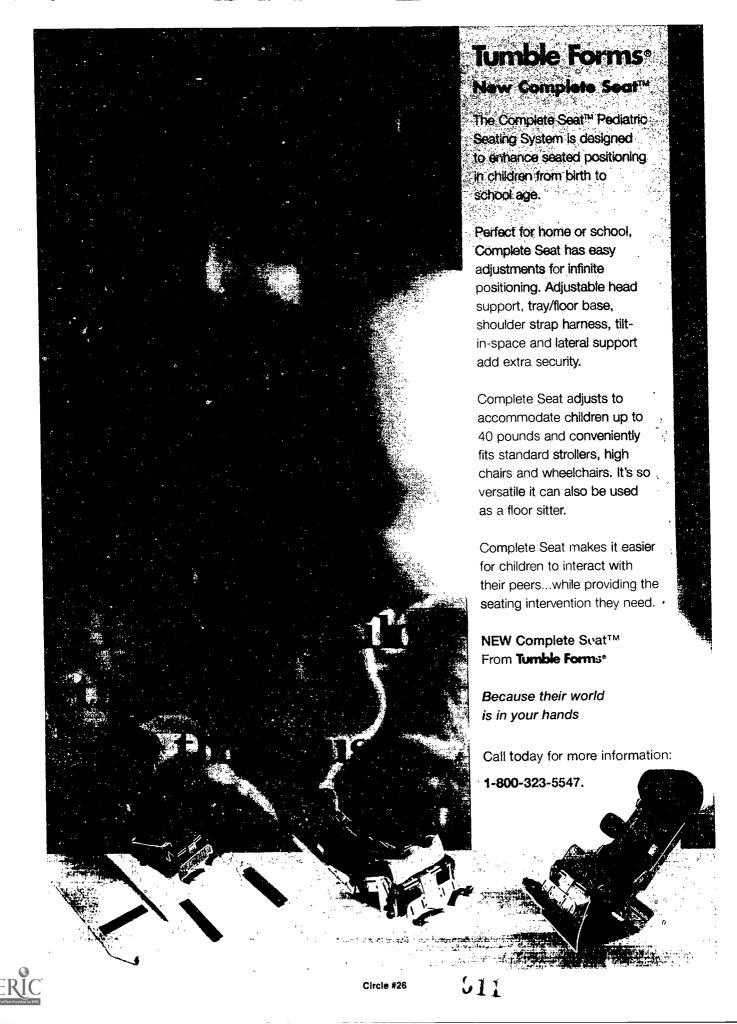
I know because my mom is part of it."

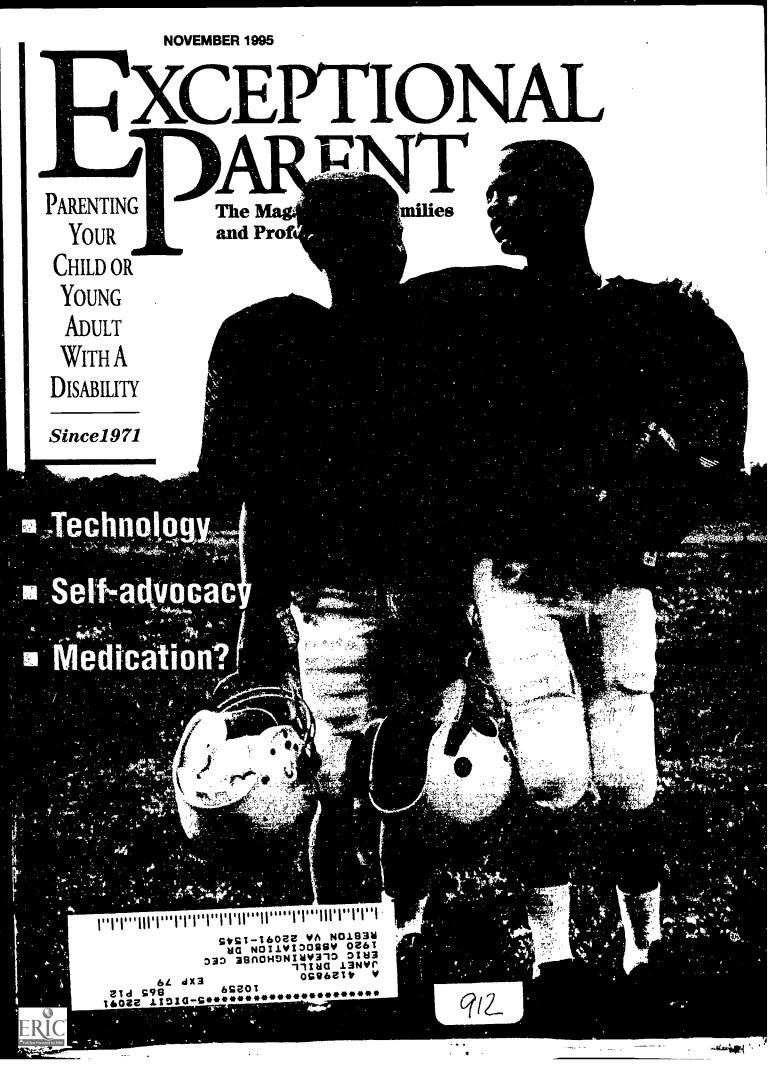


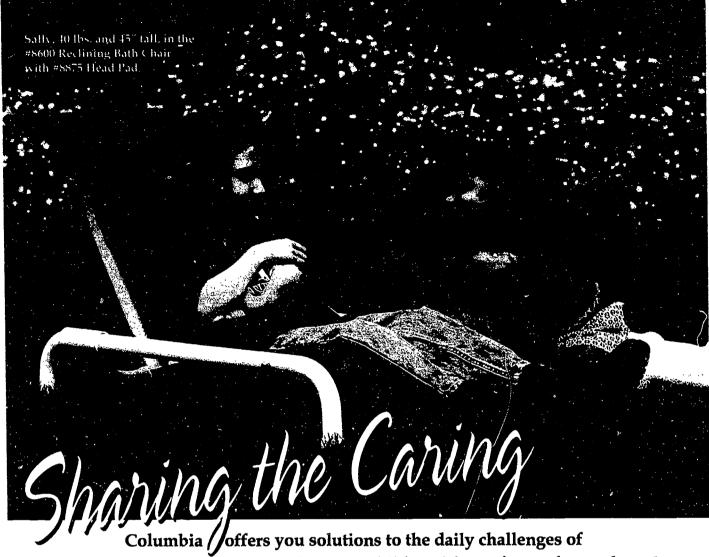
An active honor roll student, Tammie Groth doesn't believe in obstacles. Neither does her mother, Connie, one of the many General Motors employees whose own lives are affected by physical disability. It's their valuable insights that help make the GM Mobility Program work. Transportation means independence. That's something the people at General Motors know from their own experience.

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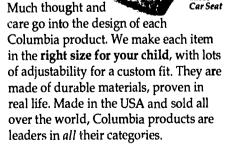
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NOVEMBER 1995 VOL. 25, ISSUE 11

**PARENTING** Your

The Magazine for Families and Professionals

CHILD OR YOUNG

**TECHNOLOGY** 

ADULT WITH A

Real People, Real Technology, Real Solutions by Bob Glass......**30** 

DISABILITY

Technology that enables children and families.

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Environmental Control by Naomi Angoff Chedd......35 "If you can operate a switch, you can operate almost anythina."

Discovering what the on-line world has to offer.

For the first time in her life, Vanessa feels totally independent.

Guest Editorial: IMAGINE THE FUTURE by Alan Brightman......41 It's about concepts, not things!

My Television Classroom by Joe Zlotek......41 New telecommunications technology allows Joe to attend school from home.

## **Features**

The First Sleepover by Jennifer Titrud	28
"All day long, Laura kept saying, 'I can't believe I'm having a sleepover!"	
"Special Ed" Deserves Special Emphasis by Rep. Randy "Duke" Cunningham	46
Using Ordinary Toys for Kids With Special Needs: ART SUPPLIES by Joanne and Stephanie Oppenheim	48
Can Medication Change Behavior? by Jason Roeder	

## **Departments**

Editor's Desk2	
Editor's Desk	
Letters4	
Search & Respond11	
Familiar Faces	
Fathers' Voices: SomeBook by Dave Jones24	
Role Models: James Meadours58	
Ask the Doctor: Feeding Aversion65	
Directory of Advertisers66	

Health Insurance Troubleshooter: Coverage for Special Formulas	70
Children's Health Notes	71
What's Happening	76
Media: Medical & Surgical Care for Children With Down Syndrome	78
Exceptional Parent Library	80
New Products	82
Children's Page: OUR DIFFERENCES MAKE US SPECIAL by Aaron Wolfson	84



PAGE 22

Cover: Twelve-year-old Justin Edwards (right) plays football for Savannah Middle School in Kinston, North Carolina, where he is a sixth grader. Justin has cerebral palsy and is non-verbal. Justin's mother, Parmilla, promised her son that if he was willing to train the teachers in his regular classroom to use his new augmentative communication (AC) device, she would support him in pursuing the activity of his choice. Justin chose football. When Parmilla and one of the coaches spoke on the phone, they decided Justin could be a manager and help his teammates during practice. Justin, listening from the other room. objected heartily. Repeatedly pushing the same button on his AC device, Justin told his mother, "Play, play, play!" Parmilla knew she couldn't go back on her promise and is glad she didn't: "I had the same fears other parents have-and I was also excited." Justin now plays on both defense and first string offense-as his coach says. "he has no fear." Justin lives in Kinston, North Carolina with his brother Samuel, 7, his parents, Parmilla and Spencer Edwards, and his aunt, Maryann Savage. He is pictured here with teammate Brett Houghton (left). 11. Photo: Lindsev Hall.



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# EDITOR'S DESK

## 13th Annual Technology Issue

EXCEPTIONAL PARENT'S first technology issue (1983) described how "newfangled" personal computers were beginning to impact the lives of individuals with disabilities. None of us could have predicted the contents of this year's technology issue! In this



STANLEY D. KLEIN, Ph.D.

issue, several young people describe their on-line travels in the invisible world of telecommunications; they describe how this technology provides greater independence while preparing them for friendships in the "real world" of their "off-line" schools and communities. Other articles describe additional exciting uses of technology by children and parents.

What will the future bring? We invited Alan J. Brightman to address this question. Alan has been at the forefront of the technological revolution for people with disabilities since the mid-1980s, when he founded Apple Computer's Worldwide Disability

Solutions Group. His guest editorial takes us beyond thoughts of ever-better "gadgets" to the vision of a truly "connected" future.

## Self-advocacy

"Self-advocacy" describes individuals with disabilities taking charge of their lives and educating others in ways that are as exciting as the magic of technology. This issue's *Role Model*, James Meadours, and other self-advocates were informative participants at a recent national meeting I attended. This issue's *Youth Connections* focuses on the same topic and features the voices of high school students with disabilities talking about the need to take control of their futures.

## **IDEA** reauthorization

Many people have expressed concern about the future of the Individuals with Disabilities Education Act (IDEA). In "'Special Education' Deserves Special Emphasis," Rep. Randy "Duke" Cunningham (R-CA) may put some of these worries to rest as he describes clear, ongoing, bipartisan support for the IDEA.

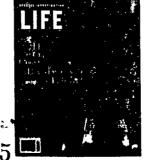
## Health care concerns

At recent annual conferences of the American Academy of Cerebral Palsy and Developmental Medicine and the National Organization for Rare Disorders (NORD), I had the privilege of meeting parents, professionals and people with disabilities, and listening to their wonderful feedback about our magazine. Many also expressed concerns about the future of health care as "managed care" increasingly becomes the favored approach. At the NORD meeting, David Hirsch, our *Ask the Doctor* columnist, described his efforts to help managed care providers in Arizona understand the necessity of appropriate care for every child, including those with complicated needs. Next month, we will begin to present information about managed care and its implications.

EXCEPTIONAL PARENT had the privilege of collaborating with NORD to present its largest conference ever. Kim Schive, David Hirsch, Joe Valenzano and I participated as speakers and were able to meet informally with many readers, while members of our fine staff assisted the ever-energetic NORD team. This meeting was inspiring to all participants and a shining example of the difference one parent can make (in this case, NORD founder Abbey Meyers).

## A "must read"

The November issue of *LIFE* presents a compelling cover story of men and women who served in the Gulf War, and who are now involved in a more complicated tour of duty—parenting children with disabilities and special health care needs. Regardless of our political opinions, these parents and children deserve our attention, love and support.





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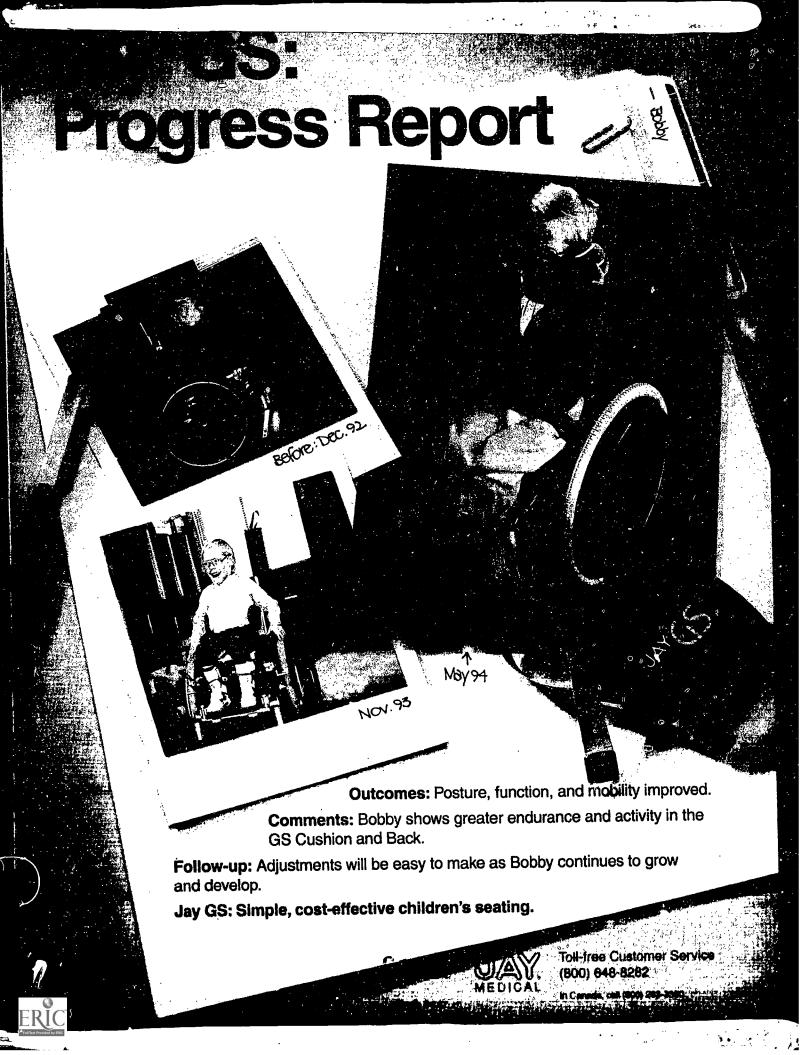
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Exceptional Parent magazine was founded in 1971 by Stanley D. Klein. Ph.D. and Muxurell J. Schleifer, Ph.D.

For subscription and advertising information, see page 58





# LETTERS

## **Respecting Choices**

I just finished reading the September issue. Thank you so much for the articles on educational choice. I was so happy to read that we are not the only parents who do not always agree with inclusion.

For several years, we dealt with a county and school district that wanted to treat our daughter just like any other "normally developing" child. That approach may be great for some children, but not for ours. Our hearts sank when the school district offered our daughter only an hour a week of individualized therapy—sessions that consisted mainly of playing peek-aboo. And then they mainstreamed her into Head Start, and told us she would learn to function like any other child just by being left alone to wander around and observe.

We are very fortunate that we were recently able to move to a larger city, and enroll our daughter, now five, in a developmental preschool where she is receiving the one-on-one therapy and individualized attention she deserves.

She is happy and thriving in this environment, learning more than she ever learned by being left alone to "observe" her "regular" classmates.

Thank you, EXCEPTIONAL PARENT, for the wonderful articles. And thanks to all the parents who stood up for what was right for their children!

K.H., Idaho

P.S. EXCEPTIONAL PARENT recently published our *Search* letter, and I wanted to let you know how pleased we were with all the responses. Thank you to all those wonderful, caring families out there!

■ Kudos on your September issue and the articles on educational choice! I support inclusion for most children, but not for my son. Those of us who do not believe inclusion is the "least restrictive environment" for our children are often made to feel like inadequate parents.

I'm glad Exceptional Parent depicted other points of view besides the prevailing sentiment that every child

should be educated in the regular classroom. Inclusion is not for every child. It never has been, and never will be. Decisions about educational placement should be left to parents!

A.J., Ohio

## These Ads DO Belong Here!

I strongly disagree with the letter from J.V.S. of Colorado (September 1995, "These Ads Don't Belong Here!") regarding Exceptional Parent's inclusion of advertisements from private educational and residential facilities.

My son, Stephen, is a beautiful, happy, social four-year-old who happens to have cerebral palsy—spastic quadriplegia with tremendous extensor tone (an abnormal pattern of muscle movement in which a child's body becomes stiff and straightens out). When Stephen lies on his back, his body becomes a rigid, 40-inch "board." I already have difficulty lifting, carrying and moving him to and from his wheelchair, standing frame, bed and play mat. Try to imagine what it will be like to do those things

continued on page 6

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health care needs and to the professionals who serve families

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continued from page 4 with the six-foot, 165-pound adult my son will one day become!

I face the reality that someday I may no longer be able to physically manage my son's needs. In fact, I have already permanently dislocated a joint from lifting him. Therefore, it is a comfort to know, right now, that there are stimulating, interesting, attractive, activities-oriented, appropriately staffed facilities that may someday serve Stephen's needs. Frankly, without the knowledge that such places exist, contemplating the future would make me even more worried, nervous and guilt-ridden than I already am.

I implore everyone to understand that all children and their families have unique needs. Please look beyond your own situation and try to understand that these facilities serve a very real need for many people.

Thank you, EXCEPTIONAL PARENT, for continuing to support the concept of "choices" for parents and children. By

providing us with a range of quality information, this publication helps parents and children to make good, informed decisions based on a thorough knowledge of all options.

Carolyn Das Michigan

## **Not Just For Parents!**

Last year, when I began working at a school for children with developmental disabilities, I picked up a copy of EXCEPTIONAL PARENT for the first time. I loved it! I immediately ordered a subscription for myself and have enjoyed it ever since.

I am in college studying to become a special education teacher and have found Exceptional Parent to be an excellent resource. I learn so much from the articles. The magazine also gives me access to products and organizations.

Many times, when I read an article I can relate it to a child I have worked

with. These articles give me a better understanding of families and the frustrations they face.

I just want to thank you for such a wonderful magazine, and thank the parents who take the time to write. EXCEPTIONAL PARENT is invaluable not only to parents, but also to professionals and teachers.

K.S., Colorado

## Rhizotomy

The article "Selective Dorsal Rhizotomy" (August 1995) and the stories from families ("Go For It!" and "Evaluating Success") were interesting to me because my son, Dustin, had this surgery five weeks ago. Like Sean in "Evaluating Success," Dustin's spasticity prior to surgery was so strong it was difficult to hold him or get him into his wheelchair—he had an "extensor thrust from hell," so to speak.

Dustin has fought some valiant continued on page 8

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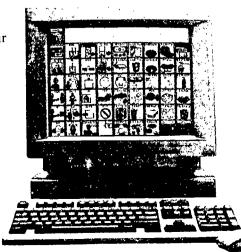
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## Opening The Door To Success



Throwing items, turning over furniture, pulling hair ... the list continues. For Adam, summers mean more than hayrack rides and swimming. They mean concentrated training, lifeskills, and measurable gains through Heartspring's Summer Intensive Behavior Program.

Adam, 10, has autism and during his first few days of the summer program at Heartspring, he averaged about 45 acting-out episodes a day. Heartspring staff members developed a plan to interrupt destructive and aggressive behaviors and to teach Adam more appropriate ways to communicate his needs and frustrations.

They used reinforcers, such as Adam's favorite foods, raisins and apples, and a trip to the local amusement park. A special picture system was developed to help Adam communicate his wants and express his feelings. His program also included around-the-clock extensive behavior management. By the end of the seven weeks, Adam's daily episodes of acting-out had decreased nearly 90 percent.

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## LETTERS

continued from page 6

fights with his spasticity. While in kindergarten, he wrote the article "Dustin's Trip to Space" (January 1990), using his letterboard. He continued in an integrated school setting until he was ten. He wrote stories, won writing awards, did well academically and learned Morse code as a backup to letterboarding.

However, as he grew older, and in spite of excellent seating evaluations, Dustin found it increasingly painful to be in a wheelchair. His spasticity caused him to push against the seat belt, which caused his skin to break open. I always had to move his computer switches around as his control site shifted when his pelvis moved forward in the chair. Thank goodness for Velcro!

By the time Dustin was 14, his seating problems were really out of hand. He needed to be repositioned three or four times during a short trip to the grocery store, and he had virtually lost his ability to bend in the middle. We feared he was becoming bedridden.

Here was my bright young son—a young man with terrific language skills, great motivation to communicate, enough computer equipment to launch the next space shuttle and a new power wheelchair—but unable to sit.

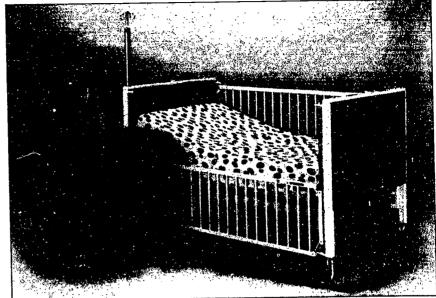
Rhizotomy held out hope. We were told Dustin was a good candidate because he was truly spastic and seemed to have some underlying muscle strength. We also had ruled out other options. Surgery would have been required to insert a baclofen pump, and I had spoken to an individual who had needed repeated surgeries before it worked properly. Likewise, Botox was not an option, because too many of Dustin's muscles were involved.

We were pleased with the rhizotomy experience. The pain control was excellent. Dustin was in the hospital for five days. He now has therapy at home three times a week. His sitting ability is amazingly improved. His comfort level is way up. And he is better able to control his computer.

Dustin's therapy sessions also have continued on page 10

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continued from page 8

changed focus. Before the surgery, the goal of physical therapy was to reduce tone. Now the goals have to do with strengthening his muscles. Dustin's head and trunk are already showing real improvement. He is back on his three-wheeled bicycle and looks forward to horseback riding.

The ultimate goal has always been to build a system that would give Dustin access to mobility and communication. We had solved many parts of this puzzle. None of that mattered, however, if Dustin could not sit. In effect, he was all dressed up with no place to go.

How far will the rhizotomy procedure take Dustin? We still do not know. But I can say this much now: At the beginning of the summer, Dustin spent too much time lying on the couch. Today, he is going to see *Apollo 13* with friends.

Anne Webb, California

## **Adapted Physical Education**

I was thrilled to see the June 1995 issue, which focused on recreation for individuals with disabilities and highlighted a number of recreation opportunities. However, I was dismayed to see no mention of a specialized recreation resource for students with disabilities—the field of adapted physical education.

I received my Ph.D. in adapted physical education from the University of Virginia. In fact, my dissertat: a focused on educating parents about the importance of physical education and fitness. My special interest in parents stems from the fact that I have a sister with a disability.

The law defines physical education as a direct service that is mandated for all students with disabilities. Not only are physical education services mandated, they *must* be adapted when necessary. Students with disabilities can receive specialized or individualized physical education services designed and implemented by a specialist in the field of adapted physi-

cal education. Adapted physical education is *not* a related service, so it should not be conducted by related-service personnel such as physical or occupational therapists.

Currently, all states have some kind of endorsement or certification in adapted physical education. There is a move toward national certification, meaning all physical education teachers interested in teaching students with disabilities may someday be required to obtain a national certification. On the local level, professionals at colleges or universities may be able to work with parents in doing individual assessments, itinerant teaching, attending case conferences and advocating for appropriate physical education services.

Because a student's health, fitness and motor skills are so vital in his or her transition from school to work, those of us in the field of adapted physical education feel very strongly that qualified individuals should be teaching students with disabilities. For years, we have strived to provide the most appropriate physical education services for individuals with disabilities. Our greatest challenge has been our anonymity.

Parents can request adapted physical education services only if they know about the field in the first place. Magazines like EXCEPTIONAL PARENT are vital in this education process.

Katic Stanton School of Physical Education Ball State University Muncic, Indiana

Entron's Note: To learn more about adapted physical education, send a self-addressed envelope with a 32¢ stamp to The Adapted Physical Activity Council/AAALF, 1900 Association Dr., Reston, VA 22091 (703/476-3430). You will receive information about the Council and information about ordering their publications.





# SEARCH-

## Goldenhar Syndrome, Esophageal Defects

My 19-m, ath-old son, Casey, has been diagnosed with Goldenhar syndrome, a craniofacial disorder characterized by poor development of facial structures. He was also born with esophageal atresia (undeveloped esophagus) and tracheoesophageoal fistula, or TEF, meaning that he had an abnormal passage connecting his trachea (windpipe) to his esophagus (the tube that carries food from the throat to the stomach).

My husband is in the U.S. Army and served in the Gulf War. We wonder if our son's birth defects are related to the immunizations and medications my husband took to protect him from chemical exposure.

I hope to get in touch with parents of children with similar problems, especially Gulf War veterans.

M.M., Maryland

Entron's Note: The following organizations can put you in touch with parents of children who have conditions similar to that of your son:

- Goldenhar Syndrome Research & Information Fund, 8829 Gleneagles Ln., Davien, IL 60561; (708) 910-3939, (708) 910-4065, fax.
- TEF/VATER Support Network, c/o Greg and Teri Burke, 15301 Grey Fox Rd., Upper Marlboro, MD 20772; (301) 952-6837.

In addition, you may want to contact the Association of Birth Defect Children (ABDC, 827 Irma Ave., Orlando, FL 32803; 407/245-7035). ABDC serves as a clearinghouse to provide free information about birth defects, particularly those thought to be associated with toxins. In recent years, ABDC has documented a variety of hirth defects thought to be associated with parents' participation in the Gulf War. ABDC helps parents of similar children make contact with each other, and offers free participation in a national birth defect registry through a 24-hour, toll-free registry line (800/313-2232).

## Krause-Kivlin Syndrome

My nine-month-old daughter was diagnosed with Krause-Kivlin syndrome at the age of six months. The syndrome includes brain anomalies; Alyssa has the Dandy-Walker malformation (a type of congenital hydrocephalus caused by a structural defect in the brain) and seizures. She also has several severe visual problems (glaucoma, microcorneas, cloudy corneas, no lenses and a short optic nerve on the right side), a ventricular septal defect (a heart condition in which there is an abnormal opening in the wall separating the left and right ventricles, or pumping chambers), a kidney defect (grade IV reflux) and failure to thrive.

Because this is a very rare syndrome, doctors have not been able to tell me what the future holds for Alyssa medically, visually or developmentally.

I would like to hear from other parents who have an older child with Krause-Kivlin syndrome or professionals who know a child with this diagnosis.

G.R., Pennsylvania

## Galactosemia

Our five-month-old son has galactosemia. This is a rare, genetic, metabolic disorder characterized by an inability to metabolize galactose (milk sugar). Children with galactosemia may have mild to severe developmental delays, and may develop cataracts, kidney problems and liver disease. We would like to hear from other parents who have a child with this condition.

B.L., Ontario, Canada

EDITOR'S NOTE: Parents of Galactosemic Children (2871 Stagecoach Dr., Valley Springs, CA 95252; 209/772-2449, voice/fax) can provide further information on galactosemia, and can help you contact other parents of children with this metabolic disorder.

## **Biting Problem**

My 18-month-old son, Ryan, was born with brain stem hypoplasia (the center part of his cerebellum is missing continued on page 12





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Circle #186



## SEARCH

continued from page 11

and his mid-brain is one-quarter the normal size). There is no known cause, but the result is third nerve palsy and Homer syndrome (a type of facial paralysis), affecting his right eye. He also has myoclonic seizures, mild cerebral palsy and probable profound mental retardation.

He can't hold his head up for more than a few seconds. Nor can he sit up, roll over, hold a toy in his hand or even smile. And he never ever cries.

What he *can* do is get his right hand to his mouth. This would be terrific except that he has a very strong bite reflex, so every time his fingers go into his mouth, he bites down—hard. Although he tries, he can't pull the fingers out of his mouth until the reflex is completed. By that time, his fingers are bleeding.

We've tried putting a slipper over his hand and fastening it around his wrist. That worked well for awhile, but now he bites his fingers through it and sometimes pulls it off. We've also tried taping his fingers around a rattle or teething ring, but he soon wiggles

continued on page 15

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax: Search or Respond, Exceptional Parent 209 Harvard St., Ste. 303 Brookline, MA 02146-5005 Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812. (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in Exceptional Parent's 1995 Resource Guide (January 1995).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "vet-ran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (Fax).

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continued from page 12

his fingers out of the tape. In addition, the tape is hard on his skin.

I would like to hear from anyone who can suggest a solution that doesn't involve restricting his arm movement. I'd also like to hear from parents of other children with profound mental retardation.

C.H., New York

## Cohen Syndrome

Nicholas, now 15, was the first of our three children. He was initially diagnosed as "developmentally delayed, with speech and language impairments." Later, his diagnosis changed to Prader-Willi syndrome, but he eventually "out-grew" the characteristics of that disorder. Two years ago, he was finally diagnosed with Cohen syndrome.

Cohen syndrome is a rare genetic disorder characterized by low birth weight, mild to moderate mental retardation, delayed growth, obesity of the trunk occuring during middle childhood and muscle weakness. Children with the syndrome have an open mouth with prominent lips and upper central incisors. They are also very tall.

If your child has been diagnosed with this rare disorder or you know someone who has, please contact us. We want to know what the future may hold for our son in terms of education and employment.

A.R., Virginia

## **Calling 9-1-1?**

My eight-year-old son has severe difficulties with speech. I am worried about what would happen in the case of an emergency that required him to use the telephone to summon help. I can teach him to dial, but he wouldn't be able to give his name, address or any other information to the 9-1-1 operator.

I have talked with other parents whose children's disabilities involve speech. They all have the same concerns. I would like to hear from anyone who has found a solution to this problem.

B.L., Pennsylvania

## Chromosome 11q-

At three weeks of age, our 11-monthold son was diagnosed with a chromosomal abnormality involving a partial deletion of the long arm of his eleventh chromosome. His symptoms include craniosynostosis (premature fusion of one or more plates in the skull), development delays and heart defects. Only 33 cases of this condition have been reported since its discovery in 1973.

One networking organization (the National Organization on Rare Disorders) has been unable to help us make contact with another family dealing with this disorder. We are hoping to find such a family among the readers of EXCEPTIONAL PARENT.

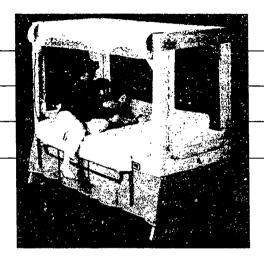
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# RESPOND

## **Colorful Brace Stockinettes**

E.L. (May 1995) has a four-year-old daughter who wears bilateral KAFOs (knee-ankle-foot orthoses) and uses 'brace liners," cotton stockinettes that absorb perspiration and prevent the plastic of the braces from sticking to her legs. E.L.'s 'fashion-conscious' daughter would prefer more colorful leggings, but tights make diapering and toileting too difficult. E.L. was seeking a source for purchasing colorful brace stockinettes.

When my daughter, Amanda, wore orthotics, we also had trouble finding socks she liked. One solution turned out to be ordinary boys' tube socks. We bought them in a large size so they went up to her knees. There were many advantages—tube socks were very inexpensive and readily available. They also wore well and stayed up.

Amanda was delighted to have socks in different colors. I was never able to find tube socks for girls, however, so our color selection was limited to darker colors like navy, red and black. Some styles have stripes, too. This may be a good way to supplement your daughter's wardrobe.

B.C., New Jersey

## **Swinging Objects**

C.T. (April 1995) has a 10-year-old son with Down syndrome. He also takes Synthroid for hypothyroidism. Since a young aye, he has had a tendency to focus on objects that he can hold and swing around. Often, as he swings the object, he talks to himself and, sometimes, spins in circles. At these times, he seems to "zone out." As he has gotten older, these behaviors have increased. C.T. was looking for suggestions to help her understand and lessen the frequency of this behavior, if not eliminate it altogether.

My 18-year-old son, Daniel, also has Down syndrome. When he was young, he liked to swing and twirl objects while spinning in a circle, usually babbling as he did so. Daniel outgrew these behaviors without any intervention.

As embarrassing as this behavior might have been to us, as strange as it might have seemed, I believe that these behaviors helped Daniel process people and events, particularly those that would otherwise have been overwhelming. If one listened carefully while Daniel spun and babbled, one could hear Daniel naming those events or people.

As I try to help Daniel find ways to cope with day-to-day frustrations now that he is 18, there are times when I am tempted to encourage him to start spinning around again.

A.K., New Jersey

## **Partial Trisomy of Chromosome One**

S.P. and S.P. (May 1995) are the parents of a 16-month-old daughter, Ashley, who has partial trisomy of the first chromosome. They have been unable to locate any other children with this chromosomal abnormality and were looking for information about this condition.

My daughter, Erin, was born with partial trisomy one. She is now nine years old—I hope that gives you something to feel good about.

continued on page 20



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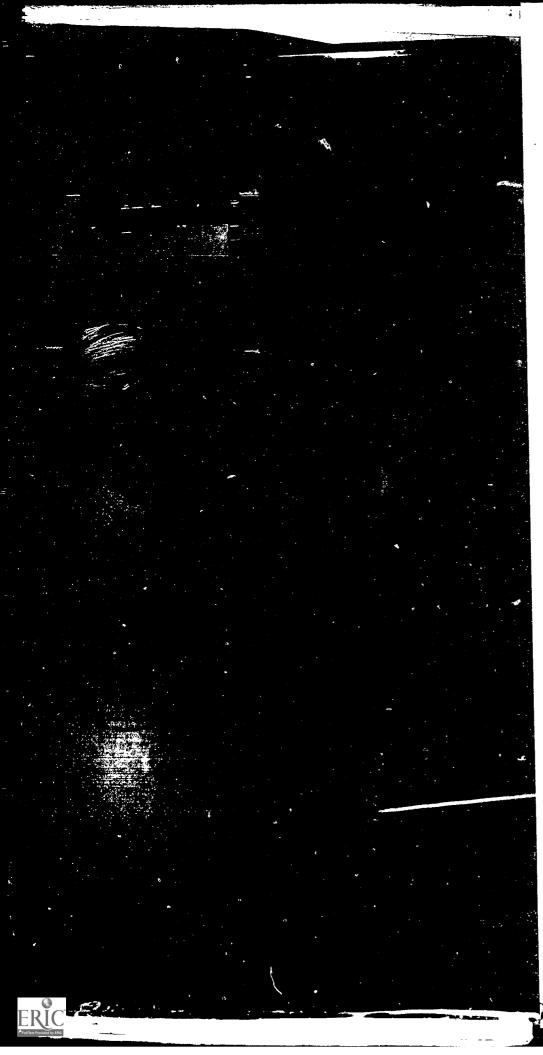
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When Erin was born, she was put in a special care nursery because her body temperature would not regulate. In that nursery, a heart murmur videtected and x-rays indicated a problem with her lungs. Her pediatrician suggested genetic testing.

When Erin was three months old, she was diagnosed with partial trisomy one. What stands out most clearly in my mind about that horrible day was the geneticist telling me that Erin would "probably die." She told us there were just six reported cases of the disorder. These six cases included two brothers who lived into their forties (they had no heart problems but had very severe mental retardation) and three girls who had heart problems; all three died by the age of 16 months. The sixth case was a sibling of one of these three girls who was diagnosed prenatally by amniocentesis and aborted. Since Erin had a heart condition like all the babies who died, the doctor did not give us any hope.

I lived the first 16 months of Erin's life wondering every morning if she would be alive when I walked into her bedroom. I always felt that if she could make it to 16 months, she would have "beaten" the others and would make it. But I was afraid to love her for fear that I would lose her. Eventually Erin's cardiologist heard about this and assured me that Erin's heart condition was so minor that, had she not been in a special care nursery, it would have gone undetected. But I have never forgiven the geneticist for those first horrible 16 months. And I have always hoped that somehow Erin's story would be an inspiration for another family.

You should see Erin today—she walks, she talks, and she has a sense of humor and a winning personality to match. She loves to swim, ride her bike and "trash" her bedroom. She has developmental delays but is 99 percent potty-trained, recognizes many printed words and knows the Pledge of Allegiance.

Erin attends a class for children with multiple disabilities within a regular public school. She is mainstreamed into regular third grade classes, mostly for socialization. She receives physical, occupational and speech therapies.

I hope that this letter brings you good news and hope. I would be so happy to talk with you at any time, and if I put Erin on the phone, I'm sure she would chat with you as well! I hope to hear from you.

K.A., New Jersey

## Supervising a "Runner"

L.K. (August 1995) has a three-yearold son, Jimmy, who has autism. Jimmy is considered a "runner," if he is not constantly supervised, he will run away. L.K. has tried using a tracking device, but Jimmy refuses to keep it on. L.K. wanted to know how other parents of "runners" deal with this problem.

I can't directly address the issue of running, but since my five-year-old son is also nonverbal, I share your concerns about identification during an emergency. In the wake of the Oklahoma City bombing, I began searching for a way of ensuring that a rescuer would be able to give an appropriate response. My solution was Medic Alert.

The Medic Alert Foundation (P.O. Box 1009, 2323 Colorado, Turlock, CA 95381; 800/344-3266) is a nonprofit organization that distributes personalized ID bracelets marked with a medical emblem and carrying a short phrase and a toll-free number. My son's bracelet says "multiple disabilities." Other possibilities might be "nonverbal," "autistic," "communication disorder" or any term you prefer. The type is small and not easily read by casual bystanders.

The toll-free number connects rescuers to the foundation's 24-hour database, which contains information you have provided. My son's information in

that database includes his name, address, birth date, social security number and blood type; my name and my home and office phone numbers; and the name and number of a family friend. It also contains the priority message that he be transported to his "home" hospital,

where he is well-known and where health care workers can access his records for a complete picture of his extensive medical and developmental history. This same information is printed on a wallet card, which I carry. (My son and I are not of the same race, so it's likely that in an accident involving multiple victims, rescuers would not immediately realize we are related.)

The Medic Alert cost is minimal, and qualifies as an IRS-defined medical expense. Information in the database can be updated at any time.

I've learned not to use the word "impossible," but the clasp on the II) bracelet is tricky enough to make it extremely difficult to remove, especially with one hand.

P.W., Illinois

■ My son also will "run" if given half a chance. To deal with the situation, we had an alarm system installed. The company was able to program it to beep any time any door or window is opened. This "beep" is not the fullsiren alert that would sound in the case of a break-in occurring when the system is "armed." And, unlike the case of a full-siren, break-in alert, the monitoring company is not notified when a "beep" occurs. I'll admit that this beep can be annoying at firstespecially when it repeatedly sounds as one is bringing in the groceries. But we've gotten used to the sound, and it has alerted us to our escapee on many occasions.

A Medic Alert ID bracelet was the other worthwhile investment we have made. The bracelet lists his diagnosis, name, phone number and the fact he has limited ability to comprehend speech.

K.G., Arizona

## Tell us about...

# ... memorable family vacations.

The last vacation stories we published (April 1995) were such a big hit, we want to do it again. Shace your stories and photos with other readers!

Write to: Readers Talk, Exceptional Parent, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.



233

# He's never gone on a sleepover before because he wets the bed.

(But tonight, with GoodNites, that will change.)



For years, he not only had to stay home while his friends enjoyed sleepovers, he could never tell anyone the real reason.

But all that is about to change. Because tonight he has Pull-Ups GoodNites disposable absorbent underpants, the first ever for larger children. GoodNites come in two sizes designed to fit kids 45 to 85+ pounds. They're plain white, like regular underpants, and thin enough to disappear under pajamas. That way no one knows they're on.

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child will wake up to clean, dry sheets; which means your child can enjoy sleepovers and vacations without worry.

It is estimated that some 3 million children—10 percent of all children ages 5 to 10—wet the bed more than once a week. The causes vary, so it's important that you visit

your pediatrician. You could be in for some good news. But one thing is absolutely certain. Your child *will* outgrow bed-wetting.

In the meantime, use GoodNites.



**GoodNites mean Good Mornings** 

Circle #133

934

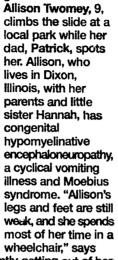


# Familiar Faces



You can't keep a good kid down! Allison Twomey, 9, climbs the slide at a local park while her dad, Patrick, spots her. Allison, who lives in Dixon. Illinois, with her parents and little sister Hannah, has congenital hypomyelinative a cyclical vomiting illness and Moebius syndrome, "Allison's

her mom, Cathy, "but she is constantly getting out of her chair and getting into things she never could before!"





Krystal Miller, 4, of Alexander, Arkansas, uses her head to push a big, red switch that turns on her tape player. Krystal, who has spastic quadriplegic cerebral palsy, loves to tease her speech therapist by waiting until the therapist leaves the room to activate the tape player. "Krystal has surprised a lot of people by doing things they thought she never would," Her mother, Maggie, writes, "but I always had faith in her."

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!



Two-year-old Brendon Kelley loves to "help" with the laundry. Brendon, who has Down syndrome, lives in Cincinnati, Ohio with his mom, Valerie, dad Patrick, and big sister, Elizabeth. "Five surgeries and eight hospital stays have not dampened his spirit or reduced his curiosity," writes his mom.



The sky's the limit for aspiring pilot Shaun Kelley, a four-year-old from Kearny, New Jersey. Here Shaun tries his hand at the controls of the STAT Flight Medivac Helicopter in Valhalla, New York. During a recent stay at the Westchester County Medical Center, Shaun, who has hydrocephalus, was treated to "flying lessons" from the Medivac flight crew.

Heeeere's Nicky! Nicholas Cugini, 4, wows the audience every night in his living room in Houston, Texas. Nicky, who has cerebral palsy, lives with his parents, Rob and Eve. He attends an inclusive pre-school and loves coloring, **Power Rangers** and books.





CEPTIONAL PARENT / NOVEMBER 1995

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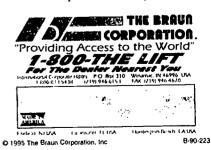
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## Fathers' Voices

# Somebody

by Dave Jones

put my son to bed tonight, the same as I have each night for most of his 10 years. Tonight, Jeff had an ear infection, which made the job more delicate. I gently lifted him from his chair and laid him on the bed. Then I looked at him in a way I suspect other parents occasionally look at their kids—really seeing them for what they are, not the image or the dream:

As I lay Jeff face down on his bed, I watch my hands carefully straighten his feet and legs I look at his hips, pulled up and to the right; his muscles take long moments to relax from sitting with a bar tight across his lap for the last few hours. As his hips settle to the surface of the bed, I straighten his back and move his shoulders to flatten his chest and free his arms.

I wait for Jeff to lift and turn his head to the left, so he can look at his tape deck, a major part of his bedtime routine. Later, he'll turn to the right, watch his night light, then sleep. On good nights, Jeff needs only one tape before he relaxes into sleep. Tonight, because of the ear infection, it may take several. The tubes in his eardrums seem to be part of the stuff kids like Jeff need. Fluids build up in his inner  $\epsilon$  ars because he can't move his head around much.

Before I kiss my oldest child good night, I straighten his fingers and wrists and lay his hands out flat on the sheet. Jeff seems to like that and smiles at me. He's got a great smile—one that hooks therapists and ordinary folks on the street alike.

I pat his head and turn out the lights, checking the room quickly to see if I've missed anything that needs doing before tomorrow. I catch a glimpse of Jeff's night brace, neglected tonight because I refuse to subject him to two types of discomfort during the same evening. Besides, he needs a good night's sleep to help him recover from the ear infection.

Jeff, 8, celebrated Christmas 1993 with his four-year-old sisters, Taylor (right) and Megan (center).





Dave and Jeff test a new HO-scale model locomotive, a Pacific Steam 462. Jeff operates the train's tranformer by using a head switch connected to a control unit.

Outside Jeff's room, I plug in the spare battery pack that hangs on the back of his wheelchair. It's not for his chair—we're still trying to find controls he can use to drive a power chair—but for his laptop computer and voice synthesizer. Many evenings, after plugging in the spare batteries, I enter the kitchen to find my wife programming Jeff's devices. She spends a lot of time making sure Jeff has everything he needs to function, both in and out of school. She also makes sure his devices include plenty of "fun stuff"—the materia! my son, the comedian, needs to "perform."

I hope Jeff stays dry tonight. He really likes to demonstrate some control of his world, a world in which he has dominion over so little. With a good start, he can time himself pretty well during the day at school; nighttime is more difficult. His toilet training has had its ups and downs, like so many other things in his life. We've learned to roll with the punches... sometimes. Other times, we punch back. Sometimes, it feels like we're taking swings in the dark.

Tonight is one of those rare occasions when Jeff's sisters are in bed before him. The birth of twins when Jeff was four was another adjustment in our lives. Now six, the girls have timidly started asking "Jeff questions." We struggle to agree on what to say and try to make sense of it for them. We've always tried to be honest about Jeff's birth injuries and what they mean. In many ways, Megan and 'Taylor are typical kid sisters who look up to and love their big brother. In school, they draw pictures of their family in six-year-old, stick-figure fashion. In each picture, the wheels on Jeff's chair are huge and Jeff is tall in the seat. There are a lot of smiles in their pictures. I like that.

I head downstairs. Maybe I'll write a bit, maybe watch some TV. After a while, I'll go to bed. Tomorrow morning, I'll be ready for the cleaning up, toileting, stretching and dressing that will begin another day with my son.

"Wouldn't it be nice," I think, "if—just for a few moments, maybe a few days—my kid could be just 'somebody' or 'somebody's kid,' instead of 'the kid in the chair?"

637

· intrined on page 26



EXCEPTIONAL PARENT / NOVEMBER 1995

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rebates are also listed in this comprehensive booklet. "Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

# Betsy will outgrow her toy before she outgrows this seat



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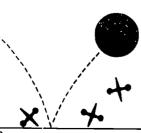
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Circle #272



In November 1994, Jeff and his friends marked his tenth birthday with a bowling bash.

continued from page 24

I wouldn't have to worry about the fast-approaching time when he's going to ask about himself. He's going to ask me, and I will answer him truthfully. My answers will be the only ones I can give, and Jeff will draw his own conclusions. He always has. **EP** 

Dave Jones lives in Northbrook, Illinois with Stacey, his wife of 12 years. They have three children—twin daughters, Megan and Taylor, 6, and son, Jeff, 11. Dave is a physical education, dance and drama teacher at Pleasant Ridge School in Glenview, Illinois. He volunteers for the American Heart Association of Metropolitan Chicago, last year coordinating the Pleasant Ridge School's participation in the Jump Rope for Heart program, which raised almost \$20,000. He also plays bass clarinet in the Northshore Concert Band, which has performed throughout the U.S., Canada and Europe.

In his spare time, Dave enjoys basketball, racquetball and working on a model HO-scale railroad. His rail system currently includes three trains; Dave is now working on the creation of three separate power systems to allow Jeff to operate individual trains with press switches.

Fathers' Voices is a regular feature of EXCEPTIONAL PAKENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellewie WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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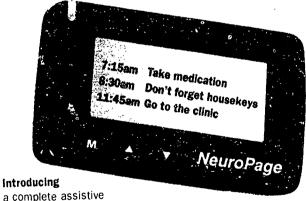
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Circle #278

# The First Sleepover

by Jennifer Titrud

aybe I'm old-fashioned, but I always thought I'd have a rule that neither of my daughters would have a sleepover until she was eight years old. That seemed a reasonable age. An eight-year-old probably wouldn't get homesick, nor would she be likely to become overly rowdy when it was time to settle down for the night.

That rule went right out the window when my second daughter, Laura, was born with a cloacal anomaly, a birth defect involving the digestive, urinary and reproductive systems. At the age of two, my older daughter, Emily, quickly learned all about "sleeping over" at her best friend's home. She participated in many hastily arranged overnight visits to accommodate Laura's frequent emergency trips to the hospital.

By eight, Emily was a veteran of sleepovers at the homes of several friends; she'd even reciprocated a few times. I was ready to concede that my "eight-year-old rule" had been too stringent, but how would I deal with Laura, now six and clamoring for a sleepover of her own?

I confess that I tried to sidestep the issue by using that old standby answer—"we'll see." I wasn't really surprised when this didn't work; children who have been through multiple medical problems and surgeries seem to end up with a particularly strong streak of persistence and faistings. In a side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the side of the

sistence and feistiness. In no time at all, Laura had three

Jennifer Titrud lives in Fairfield, Connecticut with her husband, Blake, and daughters, Emily and Laura. Jennifer is the editor of Partways, a resource publication of Parents Acailable To Help (PATH), a support network of parents of premature babies or children with medical problems in Connecticut and surrounding states.

Laura, now 7, is a second-grader at Stratfield School in Fairfield. Over the past year, she's had several sleepovers and recently spent the night in a backyard tent with her dad and sister. Mom chose not to join the rest of the family for that particular adventure.



"Let's go, Mom!"

Overnight bag and favorite doll in tow, six-year-old Laura Titrud, couldn't wait to leave for her first sleepover at the home of her friend. Melissa.

friends who were begging their mothers to have her sleep over and, amazingly, three mothers who were saying, "Sure, no problem."

No problem? Excuse me, but are you thinking of the right child? This is Laura Titrud. She spends her nights hooked up to a feeding pump and a bedside two-liter urine drainage bag attached to her urostomy pouch. And don't forget the nebulizer treatments. Then there's that little problem with bowel incontinence and diarrhea. Do you really enjoy starting the day with a few loads of laundry?

Much to my surprise, these mothers still answered, "No problem." We began to make plans, but over the winter one virus after another hit either Laura or one of her friends. We decided to wait until spring or summer.

Early in the spring, I had a thought: I wondered if Laura could be off the feeding pump for one night. At the time, Laura was taking in about one-third of her calories orally, and drinking water when thirsty. But if she could be off the feeding pump for a night, perhaps her urine output could be contained in the urostomy pouch. A sleepover would be a whole lot easier to manage without a feeding pump and bedside urine drainage bag.

One night I got up my courage and gave it a try. I'll admit I was alarmed when I saw how dark and scant her urine was the next morning—I have vivid memories of Laura as a very sick and

dehydrated baby. But after emptying her pouch, Laura went straight to the sink and drank a big glass of water. Then she proceeded to rummage around in the refrigerator and eat up a storm. (This from the child whose first spoken sentence was, "I don't eat!") The experiment was such a success that, after consulting with Laura's doctors, we decided to try one night a week off the pump.

During the spring we also experimented with different enema programs. The idea of a sleepover became a real motivator for Laura because she realized enemas would help prevent accidents during the night.

In July, the big night finally came. All day long, Laura kept saying, "I can't believe I'm having a sleepover!" It was a



Laura (left) and friend Melissa Flynn (right) enjoyed playing in Melissa's backyard.

triumph for her to feel such control and normalcy in her life. And I'll admit it—the sleepover was probably a much-needed break from an overprotective mother. I did stop by twice that evening to check on her. and I phoned at eight the next morning, but otherwise, I restrained myself admirably.

ALL DAY LONG, LAURA KEPT SAYING,

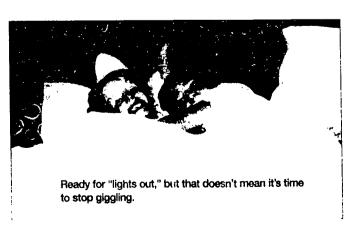
"I CAN'T BELIEVE I'M HAVING

A SLEEPOVER!" IT WAS A TRIUMPH

FOR HER TO FEEL SUCH CONTROL

AND NORMALCY IN HER LIFE.

I still break out in a cold sweat when I see my older daughter leave for a Brownie sleepover or watch my friend's sixth-grader go on a four-day field trip to upstate New York. How will Laura ever man ge those things? Then I focus on the present again, and realize we have succeeded in making Laura's life as normal as possible. I'll continue to pursue that goal, and I know Laura will be pushing and prodding





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Circle #89

ExP 1195

The Alliance for Technology Access presents...

# Real People, Real Technology, Real Solutions

The Alliance for Technology Access (ATA) is dedicated to redefining human potential through the empowering application of technology for children and adults with disabilities. Now numbering 42 centers in the United States and Canada (see list beginning on page 43), ATA provides opportunities for people with disabilities, their families, friends, advocates and service providers to get hands-on experience with the ways assistive technology can enhance independence, achievement, productivity and quality of life. Working in collaboration with more than 70 technology developers and manufacturers, ATA

centers are equipped to provide the latest information about available products and services.

The ATA is working to change the way people think about their own potential and the way they view technology—not as a luxury, but as an essential tool. Each center is ready to help potential users of technology become familiar with today's exciting technological advances. Through demonstrations, consultations, seminars and a myriad of other activities, more than 100,000 people each year are discovering new technologies that significantly enhance their lives. In the next few pages, we share a few of their stories....

## Ann Moore Technology breaks the cycle of failure

nn Moore is a bright, popular 10year-old living in Ormond Beach, Florida. Ann, who has spastic cerebral palsy and a severe visual impairment, attends Palm Terrace Elementary School, where she is an enthusiastic participant in her fourth-grade class.

But just two years ago, neither Ann nor her family could have imagined her current level of success and achievement. For six years, her parents, Beth and Bill, had worked with teachers and therapists to develop an appropriate educational program for Ann. Each year, the IEP team came up with an instructional plan to help Ann learn to communicate and demonstrate her understanding of classroom instruction. And each year, her parents, teachers and therapists experienced failure in helping Ann attain those goals. As often happens when failure becomes repetitive, expectations began to diminish.

Early in the summer of 1994, Beth and Bill decided to call CITE (Center for Independence, Technology & Education), the ATA center in Orlando. When staff members encouraged them to attend the CITE summer "computer camp" with Ann, Beth and Bill were inclined to believe the effort would be futile. After all, their daughter's school had all but given up on her, and Beth and Bill were beginning to lower their own



Assistive technology allows 10-year-old Ann Moore to show her parents and teachers what she can do.

expectations. But despite these doubts, Beth agreed to attend the camp with Ann and her older sister, Ellen.

That summer turned out to be a turning point in Ann's life as her family explored new ways to communicate with her. CITE staff members assembled a wide array of communication devices and switches for Ana and her family to evaluate—everything from simple, switch-activated, battery-operated, three-selection scanners that allowed Ann to choose among three **pre-re**corded spoken messages with the touch of a switch, to more sophisticated devices like a Macintosh computer with Speaking Dynamically (Mayer-Johnson, Solana Beach, CA), a communication program that allowed Ann to create original sentences by selecting from a menu of pictures. 543

Beth and Bill had never seen equipment like this. Neither had Ann, but she responded enthusiastically. Almost immediately, Ann was able to use these devices to indicate her preferences.

Ann's parents left camp determined to make these new tools and ideas a regular part of Ann's daily life. Beginning with switches, they discovered that Ann, even with her limited hand movement, could operate a wheelch: ir-mounted switch quite reliably with her left hand. Soon she was using switch input to operate a Macintosh computer. She quickly progressed to Co:Writer, (Don Johnston, Wauconda, IL), word-prediction software that provided her with increased speed in writing and communicating. Because Ann has a visual impairment, she used Enlarge (Berkeley Systems, Berkeley, CA), a software product that provided her with large print on the computer monitor.

No longer did family members need to make guesses about Ann's likes, dislikes and choices. Now Ann could choose her own clothes and let her family know which videotape she wanted to watch. It was exhilarating to see Ann making so many choices, communicating her needs and desires, and, finally, demonstrating the knowledge and understanding her parents had always believed she possessed.

By the time school resumed that fall, Beth and Bill were full of ideas to share with the teaching staff at Ann's school. The school purchased a Macintosh computer and necessary access devices for

ERIC¹

EXCEPTIONAL PARENT / NOVEMBER 1995

Ann's use. Not only did she begin to experience academic success for the very first time, thanks to the computer's speech output function, Ann also became able to communicate clearly with her teachers and classmates.

Each of Ann's accomplishments has encouraged her to attempt more. Ann's success also encourages her parents and teachers, who now realize that she is bright and can learn. "The Moore family has found a new hope for our beautiful day ghter and sister," says Beth. "We found that hope at CITE."

#### Lauren Scrivo Technology makes inclusion work

ight-year-old Lauren Scrivo of Fairfield, New Jersey has been a technology user much longer than most of her young friends. Lauren was born with congenital nemaline myopathy, a form of muscular dystrophy, and her parents, Linda and Peter, quickly realized that assistive technology could play an important role in her life. In fact, it was Lauren's preschool teacher who first recommended that the family visit the Center for Enabling Technology (CET), the ATA center in Whippany, New Jersey.

By the time Lauren entered first grade, she was doing all her writing with a minikeyboard and computer. This worked well for some time, until, because of her disability, Lauren experienced a decline in her range of motion and hand strength. Soon just a small amount of word-processing caused fatigue.

By second grade, Lauren was unable to keep up with the writing demands of her class, demands her parents knew would only increase in higher grades. Lauren and her family returned to CET to search for solutions.

As Lauren and her parents tried out available combinations of hardware and software, they discovered two promising options. The first was Kemx (Don Johnston, Wauconda, IL), software that allows computers to recognize methods of input other than the traditional keyboard. One Kemx option displays a keyboard on the computer's screen. This allowed Lauren to do word processing by using a trackball—a device consisting of a moveable ball on a stationary

base—to move the on-screen cursor. Since only small hand movements were required, Lauren was able to move the cursor around the on-screen keyboard quickly, and with little fatigue. But choosing letters from the on-screen keyboard required Lauren to push a button on the trackball, and this proved still to be too tiring.

The second option Lauren's family discovered at CET was the MagicWand keyboard (InTouch Systems, Spring Valley, NY). The small MagicWand keyboard responds to the light touch of two pens on the keys. This option required a very small range of motion and no pressure, so Lauren did not become fatigued while using it. And by combining the MagicWand keyboard with Co:Writer, Lauren was able to work even more quickly.

With CET's support, Lauren's parents worked with her school to purchase these important new tools and to provide Lauren with her own personal



The MagicWand keyboard, paired with wordprediction software, allows eight-year-old Lauren Scrivo to type quickly and with little fatigue.

classroom computer. In addition, the school also made architectural modifications so every part of the building is wheelchair accessible. "Everyone at the school—from the principal on down—has embraced the concept of full inclusion and is committed to making Lauren's experience a success," says her mother. "We have nothing but praise for their efforts."

continued on page 32

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#### Jennie Shaw Technology reveals hidden abilities

A ssistive technology often reveals considerable ability where little had been assumed to exist. This was certainly true for Jennie Shaw, whose first encounter with a computer took place at the age of seven.

Jennie was born with an arachnoidal cyst on the left side of her brain. The cyst had clearly affected her fine motor skills, and she was also non-verbal. Jennie's occupational therapist referred the family to Technology Assistance for Special Consumers (TASC), the ATA center in Huntsville, Alabama.

To everyone's surprise, when seated at a computer keyboard, Jennie showed an immediate ability to type, even alphabetize, simple words. Her teachers had not even been sure Jennie was able to recognize letters. Jennie's mother, Vickie, began developing a vision of what her daughter might accomplish with technology.

For starters, it was clear that some type



Jennie celebrated her twelfth birthday with her augmentative communication device by her side.

of augmentative communication (AC) device would be crucial. At TASC, Jennie was able to evaluate a number of devices. The Liberator (Prentke-Romich, Wooster, OH) was most effective.

Jennie's newfound communication abilities have helped her family and teachers learn more about her abilities. Her teachers now realize that when spoken instructions are also provided in written form, Jennie's comprehension improves remarkably. Jennie's reading abilities also surprised both family and teachers. Now 12, she reads at the ninthgrade level and appears to have been a very good reader for many years.

Currently, Jennie spends half-days in

a regular third-grade classroom in her hometown of Fayetteville, Tennessee. She attends regular reading, writing, music, physical education and art classes, and spends the rest of her time in a classroom for children with learning uisabilities. Her goals include being fully included in regular third grade social studies and science classes before the school year is over.

### Anthony Notte Technology is the equalizer

nthony Notte, a bright five-year-old with spastic quadriplegic cerebral palsy, has been using computers since he was 15 months old. In fact, Anthony's family was referred to the Computer Center for People with disAbilities (CCdA), the ATA center in Shrewsbury, New Jersey, by professionals in Anthony's early intervention program.

Anthony's first speech therapist believed it unlikely that Anthony would ever be able to talk. It seemed reasonable to

continued on page 34

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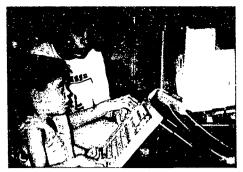
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believe that a computer might be a part of an augmentative communication system he could use. Soon, however, his speech began to develop quite well. At that point, the focus of Anthony's computer use was shifted to written communication.

Soon Anthony discovered IntelliKevs (IntelliTools, Richmond, CA), an alternative keyboard with large keys that respond to a light touch. The keys can be configured in various ways for ease of use; for example, Anthony's first keyboard was arranged in alphabetical order.

But when Anthony became old enough to attend a preschool program, Joyce discovered that his teachers were completely unfamiliar with the assistive technology that had become "old hat" for fouryear-old Anthony. The staff of CCdA worked with the family and Anthony's teachers to make the school district aware of his technology needs. The school district purchased the devices he would need and CCdA staff worked to familiarize school personnel with its use.

Now in kindergarten, Anthony is one of the most technology-savvy kids in



At five, Anthony Notte is one of the most computer-savvy kids at school.

school. He's moving away from IntelliKeys as an input device, and now does much of his writing using a regular keyboard with a keyguard (a plastic keyboard overlay with holes over each key to prevent the accidental pressing of more than one key at a time).

Technology is an equalizer for Anthony. He might not be very good at stacking blocks, but when he uses the computer, he feels confident and successful. And since few kindergarten children have access to a computer, Anthony is also an object of fascination and, perhaps, a small amount of envy among his classmates. EP

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Circle #42

ost of us perform routine tasks day after day without ever realizing how much control we actually have over our environments and our lives.

For children with disabilities, especially significant physical limitations, controlling the environment has been difficult at best, sometimes impossible. For some kids, just turning on a bedside lamp can present a major challenge. Over the past dozen years, however, a new and exciting field called environmental control (EC) has started to allow people with physical and/or cognitive disabilities to lead more independent lives. As Steve Tello, Director of Technology, Training and Assessments at Seaside Education Associates in Weston, Massachusetts, remarks, "If you can operate a switch, you can control almost anything."



With the Eye Slaved Pointing System, users can control icons on a computer screen through eye gaze. (Photo courtesy of ISCAN, Inc., Cambridge, MA)

nals to appliances, can be plugged into any AC outlet programmed to provide on-off control of any appliance—including lights, heat and air conditioning, audio and video equipment, doors, computers and many kitchen appliances. All electric systems in this coun-

fact, virtually anything that can be done with a button can be done with a voice speaking words, or consistent, close approximations of words.

Teenagers with physical disabilities may be especially interested in new options for using the telephone. Voiceactivated speaker phones automatically answer, dial and store numbers, and disconnect when the caller hangs up; some even work with call-waiting. Many long-distance companies sell specialized equipment. And more than 30 states administer adaptive telecomnunications equipment distribution programs that distribute free or low-cost telephone equipment to children and adults with disabilities. Available devices include big-button and hand-free phones, TTYs (teletypewriters with typewriter-like keyboards and view screens that, when connected to the phone.

## **Environmental Control**

by Naomi Angoff Chedd

#### What's new in EC?

All of us, with or without disabilities, use environmental control devices every day. Who doesn't have a remote to change channels on the television set? EC has been around for a long time; it's just getting more sophisticated.

Many EC companies are now designing products specifically for people with disabilities. These new devices and adaptations can allow almost everyone to use the telephone, answering machine, TV, VCR, stereo and most other appliances that can be operated by a switch or button. EC devices range from plate switches that require a light touch but not great strength, to sip-and-puff headsets, in which a switch is connected to a straw so the user can operate the switch by breathing into the straw. And some EC systems can be operated by eve gaze alone.

Some environmental control units (ECUs) are stand-alone, remote-control boxes, while others require connection to a personal computer. X-10 compatible remote controllers are among the most popular type of stand-alone devices. X-10 receiver modules, through which the remote controllers send sig-

try are compatible with X-10 receiver modules, thus many ECUs use the "X-10 protocol."

Other stand-alone EC devices can control televisions, VCRs and stereo equipment. For example, a channel scanner—the small box that allows viewers to "surf" through channels on a television set—can be connected to any type of switch to provide control of the both the television set and the VCR. Voice-controlled VCR programmers, which start, stop, rewind, pause and fast-forward in response to a voice command, are also on the market. In

This sip-and-puff switch can be mounted on a wheelchair and used to operate a remote control device. (Photo courtesy of Prentke Romich Co., Wooster, OH)



allow users to communicate by typing and reading) and light signalers, which alert someone with a hearing impairment to the ring of a telephone.

EC can also provide security. Many home protection systems work with phones; when the system is triggered, the phone automatically dials the police. Detection sensors protect doors and windows, reporting intrusions electronically to an emergency response service. Some systems also control thermostats, detect leaks or frozen pipes and turn house lights off or on at certain times. Parents whose children spend time at home alone or face frequent medical emergencies may find these systems particularly useful.

#### When to adapt

Even very young children can benefit from EC devices. Nancy Steele, Director of Rehabilitation Services at the Massachusetts Easter Seals Society, suggests that parents add EC devices to their home "whenever a child is developmentally ready to explore the environment." Steele points out that one of the simplest environmental controls is the switch-adapted toy, which can be used

continued on page 36

NOVEMBER 1995 / EXCEPTIONAL PARENT + 35



continued from page 35

by children as young as 12 months. But Steele also cautions parents not to *over-whelm* children with gizmos or gadgets.

Howard Shane, Director of the Communication Enhancement Center at Children's Hospital in Boston, emphasizes the importance of teaching very young children with physical disabilities that their actions can have an effect on their environment. To help children grasp this concept as early as possible, Shane suggests that parents "help their children explore and control their surroundings. Get them to turn the lights off and on, control the TV and VCR—everything they would do if they were able to crawl or walk."

You may want to start with a simple light switch, then add a switch that will operate small appliances. With a little help and know-how, you can purchase parts at a consumer electronics store and assemble a functional EC system without spending too much money. As ECUs become more popular, devices and systems will become more readily

#### How do I find out about EC?

 Ask an occupational therapist (OT) who has experience with adaptive equipment and knows your child's needs and capabilities.

Ask an OT or augmentative communication, specialist for the names of EC vendors. Most
EC vendors are happy to talk informally about your specific needs and what's generally available, as well as discuss their own products.

• If you have access to a computer on-line service, spend some time browsing. You'll find a great deal of information on environmental control and related topics—product reviews, conference schedules and possible funding sources.

 Attend an assistive technology or home automation conference where many companies exhibit and demonstrate their products. These conferences, which function like trade shows, are good places to get a great deal of information in an afternoon. You can find out about conferences in your area by consulting computer on-line service announcements, occupational therapists or any other professionals in the assistive technology or augmentative communication fields.

Call or write to RESNA, an interdisciplinary association for the advancement of rehabilitation and assistive technologies, at 1700 N. Moore St., Suite 1540, Arlington, VA 22209-1903; (703) 524-6686 (voice), (703) 524-6630 (TTY). RESNA can direct you to the federally-funded Tech Act project in your state, which can provide you with technical assistance, advice on funding sources and related information.

available, and prices will likely drop.

#### Who benefits?

Everyone benefits from EC. Children with disabilities can gain more independence and greater self-esteem. Family members, teachers, schoolmates and people in the community will perceive children with disabilities as more capable. Because EC

increases freedom and mobility, it allows children to participate in more activities and contribute more fully to school and community life. Ultimately, EC can expand each child's educational, social and career opportunities. **EP** 

Naomi Angoff Chedd is a member of the Exceptional Parent editorial staff.

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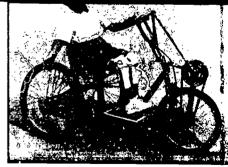
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41.

# **Exploring Telecommunications**

by Abby Albrecht

Ifirst went on-line during my sophomore year of high school. My dad had just installed America Online (AOL) software on the family's home computer, allowing us to use our computer and modem to connect to this commercial on-line service. I asked if I could try it out for a few minutes. The next thing I knew, three hours had passed, and I'd made a dozen new friends.

The high school party scene was never my thing. I wasn't into drinking, and my electric wheelchair did not fit into any of my friends' cars. So, instead of going out, I spent my time exploring everything the on-line world had to offer. I checked out the national, commercial on-line services—like AOL, Prodigy and CompuServe. I also joined several local bulletin board systems (BDSs). These small, non-commercial on-line services are often run from an individual's home and typically serve users for whom the BBS telephone number is a local call.

#### Friendships

I developed many on-line friendships with people I "met" in chat rooms or on message boards. In a chat room, you can have "real-time" discussions with others by typing messages and waiting for responses. Message boards work like bulletin boards in an office; people publicly "post" short questions or comments that can be read by anyone who visits the board, and any reader can respond by posting his or her own message. On-line relationships typically begin with exchanges in these public forums, then graduate to the exchange of private messages through electronic mail (or "e-mail").

I developed on-line friendships that were based on my personality and character, and had nothing to do with my looks or style. In fact, many of my on-line friends still don't know I have a disability. It has never come up because it just doesn't matter.



Abby Albrecht, 19, a junior at the University of Southern California, says she has made more than 100 on-line friends from all over the world.

Within a few months after my first on-line forays, my off-line friendships also began to blossom. Because of the acceptance I had experienced on-line, I began to open up to the flesh-and-blood people I saw everyday. I had gone to class with some of these kids for years, but had never made the effort to get to know them.

continued on page 38

#### **Telecommunications Leads to Independence**

The world of telecommunications is exciting. I've been on-line for more than a year, but I'm still thrilled to sign on to America Online (AOL) and hear the computerized voice say "You've got mail!"

Telecommunications technology allows me to do what every other teenager does—talk on the phone. And the best

thing about it is that there's no one looking over my shoulder! For the first time in my life, I feel totally independent.

Tuse e-mail to talk to all kinds of people on the Internet. I talk to my Uncle Eric, who works at Oracle, a large software company. He helps me with my math homework.

Lalso send e-mail to my best friend, Neetu. Neetu just went away to college so I don't see her very often anymore. This is especially difficult because I used to see her every day. I miss the times we had together. It helps that I can write my thoughts and feelings to her through e-mail.

There's lots of stuff waiting to be explored on-line. Once, I almost used an on-line service to order flowers for my sister, but Mom caught me in the act! Sometimes, I visit "chat rooms" on AOL to talk to other people who are on-line at the same time as me. Telecommunications even helps me with my homework. I can use an on-line encyclopedia and download all kinds of information. When my homework is



finished, I can even clownload games to play off-line on my personal computer

More recently, I discovered how to use my modem to access the telephone relay service for people who are deaf or have other disabilities. Before I discovered the relay, I needed help to make phone calls. Someone had to dial the number for me and turn on the speakerphone. Then I would use my augmentative communication device to have a phone conversation.

With the relay service, however, I can

use the phone all by myself. Here's how it works: I use my computer and modem to dial the relay service. A relay agent answers and places the call for me, then reads what I type to the person I have called. When that person replies, the agent types their words and I read it on my computer monitor. It is neat having private conversations; it's the first time in my life I've had secrets.

—Vanessa Coveau

Vanessa Coveau, 16, is a sophomore at Mission San Jose High School in Fremont, California.

Vanessa and her mother, Lucy, are in the process of developing a directory of teenagers with disabilities who would like to communicate with each other by e-mail. Those who wish to be included in the directory should e-mail the following information to vansc@aol.com: name, age, city, state, e-mail address and anything else you would like to say about yourself. You will receive the current directory by return e-mail.



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#### **Getting Started**

o the uninitiated, cyberspace may seem like an intimidating place. In truth, however, you need only four components to start exploring the on-line universe: a phone line, a personal computer, a modem and a subscription to an on-line service. For most people, a commercial on-line service like America Online (AOL), Prodigy, CompuServe or eWorld is the best place to start. Subscribers to one of these services receive user-friendly software through which to access the service. And if you have any problems making that initial connection, you can quickly find help by placing a toll-free phone call to the service's customer-support helpline.

Each commercial on-line service offers its members message boards, chat rooms and other special features such as up-to-the-minute news and weamer reports and on-line encyclopedias. The commercial services also provide a "gateway" to the Internet, which is a world-wide network of interconnected computer networks. Subscribers to a commercial on-line service like AOL have the capability to send electronic mail to other AOL subscribers. But because AOL (like other commercial services) is connected to the Internet, they can also send e-mail to anyone who has Internet access through any other service.

Outside of the commercial on-line services, many people obtain Interriet access through an Internet-connected computer network at their universities or places of work. Others get Internet access through local BBSs (electronic bulletin board services), community-sponsored computer networks (called "Freenets") or commercial Internet providers that charge a monthly fee and provide a local access number.

#### What's out there?

• E-mail: The capacity for users to send and receive electronic mail is often cited as the most important benefit of online communication. E-mail refers to private messages that can be written and sent instantaneously to other computer users. And unlike conventional postal services—disparagingly referred to as "snail mail"—e-mail can be sent and received at any time of the day or night.

 Mailing lists: An individual can use his or her e-mail address to "subscribe" to one or more of the thousands of available e-mail discussion groups, commonly referred to as mailing lists. Mailing lists allow subscribers to participate in ongoing discussions on almost every topic imaginable. Any new message or response sent to a mailing list is

distributed to every subscriber.

• Newsgroups: Internet newsgroups work like message boards on the on-line commercial services. More than 5,000 newsgroups (ocus on a variety of topics, Each newsgroup stores messages on a computer in a central location, and users read and reply to these messages from their own computers.

• World Wide Web: The World Wide Web provides a way to display information on the Internet. The Web is made up of interconnected "pages" (sometimes called "sites"), each containing textual and graphical information on a specific topic. To access the Web and move from page to page, users need software known as a "Web browser" Most of the commerical on-line services now offer their own Web browser software, thus providing their users with a gateway to this rapidly growing part of the Internet.

Web browser software allows you find information on any subject with the click of a mouse button. There is no need to type complicated commands. When the browser finds the location you want, it downloads (receives) the information from the computer at that site and displays it on your computer.

Take the plunge!

Chances are, some of the people you know are already on-line. Talk to your friends and find out about the on-line services they're using. Then go ahead and give it a try!

continued from page 37

My new friends, on- and off-line, all had one thing in common—they aidn't care that I used a wheelchair; they liked me for me.

Creating communities

After graduating from high school, I began my college studies at the University of Southern California.

Unfortunately, my family's computer equipment stayed home. When I could afford to buy a modem during my sophmore year, I was able to get reacquainted with AOL and the local BBSs. I was also able to get a free Internet account through the university. The Internet (an electronic network of hundreds of thousands of

interconnected networks) did not have the fancy graphics and userfriendly interface of the commerical on-line services, but I didn't care. I was anxious to explore this new dimension of cyberspace.

Around that time, a magazine I was reading suggested checking out Internet "newsgroups" about the "X-Files," one of my favorite television shows. When I went on-line looking for these newsgroups, I also discovered email discussion groups, or "mailing lists." There are thousands of these lists on the Internet. Each brings together people with a common interest—everything from a favorite television series to a college alumni association to a specific disability. For example, one of the five groups I joined revolves around David Duchovny, star of "The X-Files." It was strange and exhilerating to "talk" with people from all over the country who shared my interests and tastes.

Although members of these groups come together because of a common interest in a specific topic, I soon discovered that conversations veer into other topics as well. The anonymity of on-line conversation may make people feel more comfortable talking about subjects they would never think of discussing with off-line friends.

Karen Knight, one of my on-line friends from Duchovny-L (the "L" identifies it as a mailing list), agrees. "The gang at Duchovny-L has become my family," she says. "We talk about many things. We have rational discussions about religion, abortion, sexual orientation and a number of other issues."

On-line communities also offer people with disabilities a way to make connections with others who are dealing with similar challenges. On-line disability forums offer opportunities to share thoughts and ideas. Topics can range from personal care attendants to dating. As Rachel Stewart, one of my old friends from muscular dystrophy camp, explains, "I can't talk to my [able-bodied] friends about everything. They don't understand some of the things I've been through. But on AOL, I can talk with other people who are disabled and know what I હોલ્al with every day."

Warm fudge and soda

Last summer, "X-Files" fans who had been "meeting" on AOL for about a year, decided to take a bold step out of anonymity. Together, we planned an "AOL 'X-Files' Convention" in Las Vegas, the first of what we hoped would become an annual event. Finally, everyone who had been writing to each other for the last year would have the chance to see their friends, face-to-face.

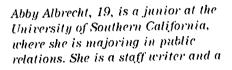
Once we were relaxed enough to speak as honestly in person as we do on-line, everyone admitted to an initial fear of attending the convention—what if they don't like me in person? But our on-line relationships had already gone beyond the superficial; looks still didn't matter. One of my friends and I spent several hours bonding over warm fudge and soda—something we could never do through a modem.

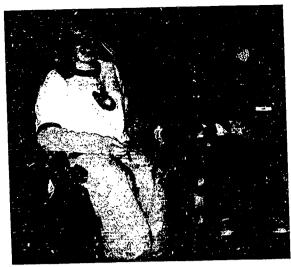
#### A valuable tool

On-line services are definitely addic-

tive. Everyone learns moderation after a while. But in the beginning, when I was trying to learn everything I could, my AOL bill was huge.

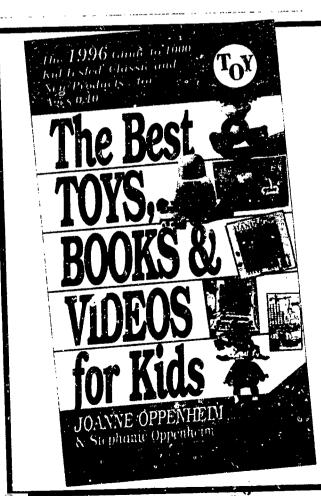
Still, it's impossible to put a price tag on what my on-line travels have given me. If I had not learned to open up to complete strangers in cyberspace, I never would have had the courage to go out and find friends off-line. And it was online communication that first sparked my interest in writing, an interest that has led me to pursue a career in public relations. Telecommunications is a valuable tool-a tool that has helped me learn more about who I am and who I can be. EP





Fourteen-year-old Rachel Stewart (left) enjoys frequent e-mail communications with her friend, Annie Wilson (right), 13, who lives an hour away, on the other side of the San Francisco Bay. Both girls have spinal muscular atrophy.

book editor for the student newspaper, The Dally Trojan. She also works in the university's Office for Students with Disabilities, where she helps other students with disabilities adjust to life on campus.



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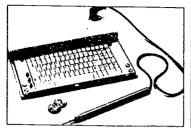
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# **Imagine the Future**

It's about concepts, not things!

by Alan Brightman

n the field of disabilities, discussions about the future of high technology seem to invariably center around things. New gadgets, faster gadgets, gadgets that do the wondrous and gadgets that do the mundane. Hardware things. Software things. Always, it seems, talk about the future is talk about some thing.

Which, in my opinion, misses what the future is really going to be about.

When I think about tomorrow and next year and five years from now, what excites me more than anything else is the idea of connectedness, no longer being isolated, making choices to participate in virtually anything.

Connectedness is a concept, not a thing. And yet, it's what I believe the future of high technology will offer to everyone concerned with kids and adults with disabilities, with their parents and family members, and with the helping professions that serve them all.

In a recent advertisement, AT&T used the phrase "long-distance togetherness." That phrase beautifully describes the future I see. Telecommunications, online services, the Internet, the "information superhighway"—you've surely heard of these things. But have you tried them yet? Have you started to experience the future?

It's time. The future is just about here.

We are experiencing the benefits of this future even today. With telecommunications, parents are consulting and commiserating with other parents in faraway states, even other countries—all for the price of a local phone call. Kids are chatting with other kids-hundreds at a time or one-on-one-sending the sound of laughter across standard phone lines. Researchers are scanning library collections in seconds, no matter where the library is located.

None of us knows where the information highway will lead. But that shouldn't stop us from beginning our individual journeys. It's okay to get lost (and you will). Like any wanderer, you will stumble upon the unexpected. And you'll be amazed by what you'll find.

continued on page 42

#### My Television Classroom

My name is Joseph Zlotek, but everyone calls me Joe. I am 10 years old. I live with my mom, dad and baby sister, Sarah. I go to Cedar Creek Elementary School in Forked River, New Iersey.

I like going to school. But last year, I couldn't go to school for five months. I had to have a tutor come to my house. I really wanted to go to school instead of having a tutor, but because of chemotherapy, I couldn't.

Then the phone company (Bell Atlantic, to be exact) called my mom. They told us we could have a special telephone hookup that would let me be part of my class from home. The telephone company people came and hooked it up in my Dad's home office.

It was really cool. It was called ISDN. ISDN stands for Integrated Services Digital Network.

ISDN let me see and hear the teacher and the kids at school on a TV at home. They had a TV in the classroom, so they could see and hear me, too. I could even read the same book as the class because of a "document camera" that sat beside the TV. The camera looked kind of like an overhead projector.

One day, my whole TV screen went black. I could still hear everybody at school, but I couldn't see them. Fortunately, I was able to fix the problem myself by using the small

control board. It wasn't a serious problem. It would have been more serious if I couldn't hear anything through the TV. Then we would have had to call Bell Atlantic. They told us they would come any time I needed them. But that never happened.

While undergoing six months of

an ISDN connection.

chemotherapy, Joe "attended" school

by television monitor in his dad's home

office, where Bell Atlantic had installed

It was great using ISDN to see everybody at school. It was great to be in class, except I couldn't go outside to recess. So I asked my teacher, Mrs. Schmitt, if a few of my friends could stay in from recess. She agreed, and we were able to use ISDN to talk and play during

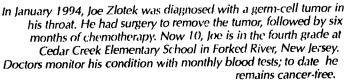
recess.

--Joe Zlotek



The document camera allowed Joe to look at the same books and worksheets as his class at school.









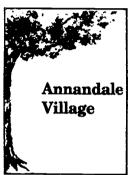
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In this connected future, we'll learn to expect the unexpected and to attain the previously unattainable.

Want to attend that all important conference, but just can't afford to hop on a plane and be away for three days? No problem: connect to the conference from your kitchen table. Listen, watch, participate—at your convenience, with just a local phone call.

Does your third-grader need to spend the next month in the hospital disconnected from her classmates, from showand-tell? No problem. Get her connected. Technology can be a bridge to what she left behind. (Can you believe some critics still argue about the anti-social aspects of high technology?)

This sounds like a possibly interesting future, you say. But aren't the nuts and bolts of it all too difficult for the average me? Not at all—especially if you already know how to use a personal computer and a telephone. It's neither complicated nor expensive. And its value will far outweigh its expense.

We have always characterized computers as the technology of independence. We've represented them that way because children and adults with disabilities viewed these devices in just these terms.

In the future, those terms will change. The technology, as a set of devices, will be no more exciting than a rotary phone. But thanks to advances in telecommunications, what we'll be able to do with that technology will bring about an unprecedented democratization of individual opportunity.

At the moment, we can only imagine these kinds of dreams and ideas. Your family should be part of that imagining. You *need* to be part of that imagining.

After all, it's not our future. It's yours.

And if you don't start dreaming about it, and making it happen, who will? **EP** 

Alan Brightman is the manager of Apple Computer's Worldwide Disability Solutions Group, which he founded in 1985.

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The Alliance for Technology Access (ATA) began in 1987 as a joint project of a grassroots organization—Disabled Children's Computer Group—and a major corporation— Apple Computer.

From this small group of parents, consumers and professionals, the ATA has grown into one of the nation's largest resources to help adults and children with disabilities gain access to the benefits of adaptive technology.

The ATA's most important means of promoting technology access may be its nationwide network of community-based assistive technology resource centers. ATA centers work with a wide variety of individuals and organizations and have no eligibility criteria for determining who may receive services. Most centers provide hands-on consultations and product demonstrations, make recommendations and referrals, and present workshops on technology use.

#### ALABAMA

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Team of Advocates for Special Kids 100 W Cerritos Ave Anaheim, CA 92805 (714) 533-8275 (voice) (714) 533-2533 (fax) E-mail: taskca@aol.com

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(312) 421-3464 (fax)
E-mail: taad@interaccess.com

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E-mail: Ilrcmi@aol.com

#### MINNESOTA

PACER Computer
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Minneapolis, MN 55417-1098
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#### MISSOURI

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continued on page 45



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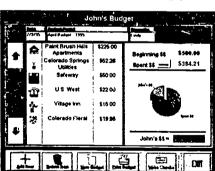


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continued from page 43.

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of Middle Tennessee
2222 Metro Center B!vd.
Ste. 126
Nashville, TN 37228
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(615) 248-6733 (V/TTY)
(615) 259-2536 (fax)
E-mail: tactn@aol.com

West Tennessee
Special Technology Access
Resource Center
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lackson, TN 38305
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#### VIRGIN ISLANDS

Virgin Ivlands Resource Center for the Disabled PO Box 1825 St Thomas, USVI 00803 (809) 777-2253 (voice) (809) 774-5816 (fax)

### The TECH TOTS Project: Technology belongs to everyone

Sarah, a two-year-old who cannot crawl or walk, is known in her neighborhood as "the kid with her own car." She gets around in a yellow, battery-operated jeep, by pressing a switch on the steering wheel, instead of the "accelerator" pedal. Sarah's mom laughingly says, "I think she drives just like her father!"

Sarah found her car at a TECH TOTS
Library, a project of United Cerebral Palsy
Associations, Inc. (UCPA). These libraries
give families of preschoolers with disabilities an easy way to try out different types
of technology—everything from toys and
computers to mobility equipment.

Today, there are 19 TECH TOTS libraries nationwide, reaching over 1,000 families of children with disabilities each year. Membership costs up to \$25 per year and varies from site to site; sliding scale options and alternative methods of payment, such as volunteering time, are available.

There are three ingredients to the TECH TOTS "recipe." First, families are in charge. TECH TOTS libraries are run by parent coordinators—family members who already know the "ins and outs" of

by Kathleen Gradel

technology. Coordinators do everything from teaching other families and youngsters to use equipment, to organizing and maintaining all equipment, to recruiting library members. A second ingredient is the equipment itself: libraries stock the full range of computers, toys, adaptive switches, mobility equipment and more. The most vital ingredient is the belief and practice that technology belongs to everyone. This means that families borrow equipment, just as they would check out books, tapes and records at the local public library, or rent a video game. TECH TOTS is based firmly on the philosophy that technology should be touched, bumped, fondled and bruised by kids, parents, brothers, sisters, grandparents and pals.

TECH TOTS believes in families being active partners in decision-making about technology—and making technology "happen" for their sons and daughters. Through TECH TOTS, families report the following: they make informed decisions—and exercise choices—about what meets their children's needs, what works and what doesn't; they are in

charge of fun and learning for their children—not in the back seat; they don't wait for someone else to introduce technology to them; they get comfortable with equipment and decide what works. Most important, we hear that kids and families get technology's enabling "bang"—that they become "doers" rather than "watchers."

For more information, write, call or e-mail United Cerebral Palsy Associations, Program Services Dept., 1660 "L" St. NW, Ste. 700, Washington. DC 20036; (800) 872-5827, (202) 775-0406, (202) 776-0414 (fax); ucpainc@aol.com (e-mail). UCPA can help you:

- Find a TECH TOTS Library in your area;
- Order materials—or get training and assistance—to start your own TECH TOTS Library;
- Donate equipment to the TECH TOTS network; or
- Sponsor a family's membership in a local library.

Kathleen Gradel is Director of the Program Services Department at United Cerebral Palsy Associations, Inc.

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Circle #14



558

NOVEMBER 1995 / EXCEPTIONAL PARENT + 45

reg is a young attorney. He does some work for a Washington-based association. California Governor Pete Wilson recently named him to a state advisory panel.

This might be the story of just another ordinary up-and-comer, except that Greg was diagnosed with cerebral palsy in infancy. His lack of muscle control slows his speech; he needs a motorized wheelchair to get around and uses a computer to write.

Greg's success would not have been possible without the Individuals with Disabilities Education Act, or IDEA, which mandated and financially supported his education. In generations past, Greg probably would have been institutionalized.

Fulfilling our moral commitment IDEA helps fulfill our nation's moral commitment to educating America's children with disabilities. Education transforms individuals who were once

thought to be helpless, into productive, working, taxpaying citizens.

The cost of providing "special ed" and other services to five million American children with disabilities is considerable. Congress contributes about \$3.3 billion to an enterprise that costs up to \$50 billion a year. But this expenditure makes excellent fiscal sense. Our investment of time and resources into education for these students spares the financial cost of lifetime institutionalization, which might cost from \$15,000 to 80,000 a year for each child. It also preserves the important contributions people with disabilities make to society.

This law is explicitly built upon constitutional rights and protections. Applying our 14th Amendment right to "equal protection under the law," it ensures that children with disabilities receive a "free, appropriate, public education" in the "least restrictive environment" based on an "individualized education program" (IEP) that is agreed to and regularly reviewed by the child's parents and school. IDEA also authorizes federal funding to help states accomplish this task.

#### A history of exclusion

Twenty years ago, children with disabilities inhabited American society's dark fringe. Very few states provided any type of "special ed" as we know it today. More commonly, schools simply excluded

# "Special Ed" Deserves Special Emphasis

by Rep. Randy "Duke" Cunningham

students with special needs from the classroom.

In the late 1960s, parents of children with disabilities began taking their outrage to court. Two cases, *Pennsylvania Association of Retarded Citizens v. Commonwealth of Pennsylvania* and *Mills v. the Board of Education of the District of Columbia*, reached the federal courts.

Pennsylvania Association of Retarded Citizens challenged that state's out-dated school code, which prescribed housing people with mental retardation in institutions because Plato's Republic recommended that "the offspring of the inferior, or of the better when they chance to be deformed, will be put away in some mysterious, unknown place, as they should be." Children with mental retardation who were "disruptive" in class, not performing at grade level, or deemed "uneducable" were sent home for good.

Things were even worse in our nation's capital. Children with disabilities roamed the streets of Washington, D.C.

The courts ruled on both cases in the early 1970s, stating that such cavalier treatment of children with disabilities violated the children's constitutional right to equal protection under the law. These rulings, followed by a growing number of sometimes conflicting cases arising in other federal district courts, motivated Congress in 1975 to enact IDEA's precursor, the Education for All Handicapped Children Act (Public Law 94-142).

During the last 20 years, P.L. 94-142 and IDEA have transformed the lives of children with disabilities in America. Once these children were neglected as a matter of practice. Today, they are educated to take part in the American dream. Many, like Greg in California, do just that.

#### Common-sense themes

The IDEA legislation is scheduled to be reauthorized this year. The House of Representatives Subcommittee on Early Childhood, Youth and Families, which I chair, has held hearings on the reautho-

rization. Our primary goal is to renew and improve IDEA to better serve children with disabilities and their families. The renewal of this law centers on five common-sense themes:

- Quality results for all students:
  Schools should be accountable for all of their students, including those who have disabilities. The IEP for each student with a disability should be a working document focusing on educational results, not a list of perfunctory services and procedures. Students with disabilities should be expected, to the maximum extent possible, to meet the same high expectations and challenging standards that have been established for all students.
- Strengthening the family's role: Parents of children with disabilities have enough challenges without adding arrogant "educrats" to their burden. When decisions are being made about their children's education, parents must be informed of their options and rights in clear, practical language. Parents must be full partners with the decision-making team, from evaluation through placement.
- "Win-win" dispute resolution: For most families, the process of determining IEPs for children with disabilities works fairly well. But when things go wrong,
  "I costs can skyrocket and drain resources away from the education of children. Instead of forcing families and schools into an adversarial legal system, we will encourage states to have a mediation process that will offer parents ways to develop educational solutions in which everyone "wins."
- Teacher preparation, during college and beyond: Children with disabilities vary as widely as children without disabilities. Classroom teachers, both in regular education and special education, must have the information and resources they need to do their jobs right.
- Useful research: Parents and teachers lack solid research results to guide them on the best educational course for chil-





dren with disabilities. The renewal of IDEA shoud lead to building a strong research base that can improve education for children with disabilities.

Discipline, inclusion and funding Most people can agree on these five issues. The areas of greatest division, where Republicans and Democrats are working hardest to build consensus, have to do with discipline, inclusion and funding.

The issue of discipline is particularly difficult because the law gives children with disabilities certain rights and privileges other children do not have. This is a product of the (until recently) sad history of schools' failure to educate children with disabilities. In the past, for example, "typical" children who disrupted a class by chewing gum may have been disciplined with detention, while children with disabilities who "disrupted" class with twitching or slurred speech were kicked out for good. Fortunately, this is no longer the case, but it illustrates the difficulty of handling discipline for children with disabilities.

Currently, a child protected under IDEA can be suspended for up to 10 days for misbehavior. During those 10 days, the school works with the child's parents to determine the best course for addressing the problem.

The Jeffords Amendment to the Improving America's Schools Act allows a special-education student to be placed in an "interim, alternative placement" for up to 45 days if the child's violation involves a firearm. However, this extended "cooling-off" period is not enough. We cannot have children with disabilities bringing guns to school, then hiding from justice behind the noble goals of IDEA.

The law needs clear procedures for removing dangerous students from the classroom, with instructions for determining whether the behavior is related to a student's disability. If a child's misbehavior has nothing to do with his or her disability, schools should have the flexibility and authority to discipline as they see fit.

The second controversy has to do with "inclusion," the practice of incorporating children with disabilities into the

egular classroom rather than segregating them in "special ed" classes. Children with disabilities can benefit from time spent in the regular classroom. Their classmates without disabilities can also benefit. However, some people argue that inclusion is difficult, inconvenient, costly, damaging to the education of students without disabilities and less than ideal for children with disabilities. In some cases, these concerns are justified. But the placement of a child with disabilities in a regular classroom is, and should continue to be, the product of careful cooperation among parents, teachers, and administrators though the development of a child's IEP. The ultimate goal of the IEP process for each student with a disability should be to find the educational setting which provides the best possible educational results—whether a regular classroom, a separate classroom or a combination of the two.

Funding will always be a challenge. When the law was written, Congress pledged to provide states with 40 percent of the funding needed to educate

children with disabilities. Today, the federal contribution of \$3.3 billion covers only about seven percent of these costs. It is difficult for public schools that are already strapped for funds, to provide costly services to children with disabilities. We will do our best to maintain funding for IDEA as we bring the federal budget into balance.

A chance at the American dream It is my hope that we will continue the bipartisan consensus supporting the education of America's children with disabilities. Their chance at the American dream depends on our determination and hard work on their behalf, through prompt and thorough renewal of IDEA. **EP** 

Representative Randy "Duke"
Cunningham (R-CA) is the chairman of the Subcommittee on Early
Childhood, Youth and Families of the
House of Representatives Committee
on Economic and Educational
Opportunities. He is a former leacher
and coach, and a retired U.S. Navy
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# 10°

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## **Art Supplies**

by Joanne & Stephanie Oppenheim



For more than 100 suggestions on how to adapt ordinary toys for kids with special needs, see the 1996 edition of **THE BEST TOYS**,

THE BEST TOYS, BOOKS & VIDEOS FOR KIDS (HarperCollins, \$12)

by Joanne and Stephanie Oppenheim. The book is a comprehensive guide to more than 1000 classic and new products for children from infants to preteens, and is available through Exceptional Parent Library (800/535-1910). rt materials are more than fun. They motivate kids to develop dexterity and express feelings, and they provide a great deal of sensory feedback. Creative exploration—without lots of rights, wrongs or rules—gives kids a wonderful sense of "can-do" power.

These art materials require little or no adaptation for children with disabilities. Most can be found in any toy store. Following the name of each item, in parentheses, is its manufacturer, the recommended retail price and a customer service number that may be used for ordering or for more information. Following the description of some items are suggested adaptations or activity tips.



#### **JUMBO DOTS • N-DASHES**

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Bypass brushes altogether! Six colors of washable paint come in easy-tograsp bottles with sponge applicators for artful, no-spill exploration. A playful way to develop the sweeping hand motions needed for writing.

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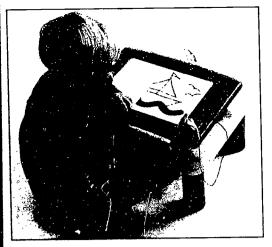
(Tyco, \$8; 800/488-8697)

. . .

Finger paint allows kids to put their fingers and hands directly in the paint. The results make the mess worthwhile; such hands-on art experiences promote satisfying sensory exploration. For kids who are reluctant to put their hands in paint, this kit has rollers with different designs.

Adaptation idea: Rollers come on broad handles that can be wrapped with velcro tape and used with a velcro-lined mitt.





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The classic magnetic board has long been a favorite mess-free drawing board. It now comes set into a small table with a well that provides a secure base, storage space for plastic building blocks and a surface for drawing. Children can sit on the floor with their legs underneath the table.

Adaptation idea: Put a roll of paper towels into the well (it fits perfectly). One end of the board will rest on the paper towels and the other end on the table so that the board is angled towards the child. Great for children who need a tilted surface.

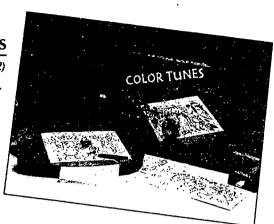
#### **COLOR TUNES**

(Crayola, \$34.95; 800/272-9652)

These two-sided, reusable, premade drawing sheets fit onto an easy-to-tote board. When a child places the sheet on the board and begins to color, the board plays a song that goes along with the picture on the sheet. Although we don't usually suggest coloring books, these may interest children who are learning to control drawing and writing tools.

Adaptation idea: Place a piece of blank paper over one of the drawing sheets so child can draw original art as he or she activates a musical accompaniment.

Activity tip: Use the premade drawing sheets for an "I Spy" game. Have child find and touch the animal that goes "moo" or "oink" in the picture.



These products were reviewed by the Oppenheim Toy Portfolio, an independent consumer organization that tests and evaluates the best products for children. The organization annually publishes THE BEST TOYS, BOOKS & VIDEOS FOR KIDS and also publishes a quarterly newsletter. Both publications include learning activity ideas and ways to adapt ordinary products for kids with special needs. To subscribe to the newsletter, send \$12 to The Oppenheim Toy Portfolio, 40 East 9th, Suite 14m, New York, NY 10003.



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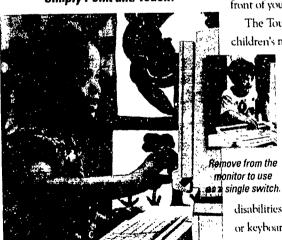
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NOVEMBER 1995 / EXCEPTIONAL PARENT • 49



# Can Medication Change Behavior?

Since the age of six, Andy Ayres* had shown the extreme distractibility and restlessness associated with hyperactivity. Andy, who has Down syndrome, constantly ran through the house turning knobs and picking up objects. He would often awaken at 2 a.m. By the time Andy turned eight, his parents, Carole and Carter, began to notice further disturbing and dangerous behaviors.

"He was riding his bike directly into traffic," said Carter: "Other times, we'd find him sitting in the road in the middle of the night."

Andy was diagnosed with a bipolar disorder—a mental illness also known as manic-depressive disorder—involving alternating phases of excessive excitement and activity (mania) and persistent, profound sadness and feelings of worthlessness (depression).

"We thought Down syndrome was the only challenge we had to deal with," said Carter: "We weren't expecting Andy to have a mental health problem..."

esearch has shown that certain behavior patterns can be directly related to specific diagnostic conditions. (See, for example, "Beyond Labels" by Karen Levine, Ph.D., October 1995.) But Andy Ayres' troubling behaviors were not typical of children with Down syndrome; rather, these behaviors turned out to be symptoms of bipolar disorder, an unrelated condition. This diagnosis led to Andy's treatment with the same psychoactive medications that may often help other individuals with the same type of mental illness-individuals who do not have Down syndrome.

#### Moving away from blame

It is not uncommon for parents or professionals to attribute a child's inappropriate or unusual behaviors or feelings to factors related to his or her disability.

* Andy's parents, Carol and Carter Agres told Andy's story in Exceptional Parent's April/May 1993 issue, in an article entitled "Tough Choice." We appreciate their willingness to share more of their family's experiences in this article.

#### About this article:

Recent research has demonstrated that the body and the "mind" are not two separate systems; rather, there are complex interrelationships between the two. Many troubling behaviors and/or emotions may be caused, at least partially, by physiological processe. These processes, in turn, may be affected by life experiences.

Much remains to be learned about these processes, and misunderstandings still occur. One source of misunderstanding is the myth that individuals are in complete, conscious control of their feelings and behaviors—that all behavior is planned, and that individuals are aware of their specific motives for behavior. In truth, the causes of behaviors and feelings are extremely complex, and disagreements about the source of certain behaviors and emotions exist even among mental health specialists.

Terminology is often another source of misunderstanding. For example, terms such as "emotionally disturbed," "psychological problems" and "mental illness" may be used to describe children, with or without other disabilities, who have serious problems in everyday life—problems controlling behavior, making friends or feeling good about themselves. Any given term, however, may not mean the same thing to everyone who uses it.

This article focuses on the use of medications to treat troubling behaviors and/or feelings in children with disabilities. It does not address controversies about definitions and labels, nor the specific qualifications and skills of various types of mental health professionals. Nor does the article discuss the misuse of medications that has sometimes occured in institutional settings where appropriate therapeutic or educational programs are unavailable.

Some professionals blame all of a child's "bad" behaviors on parental reactions to the child's disability.

Similarly, in the past, when children with mental retardation behaved in troubling ways, professionals often believed the behavior to be related to the child's intellectual limitations or dismissed it as an attention-getting device. Some people believed that individuals with mental retardation and/or communication difficulties lacked the intellectual or emotional abilty to experience mental illnesses. Perhaps most damaging, many professionals once believed

Andy Ayres, 7, enjoys an affectionate moment with his father and grandmother. "We thought Down syndrome was the only challenge we had to deal with," says his dad. "We weren't expecting Andy to have a mental health problem."

autism to be a mental illness caused by inappropriate parenting.

Much has changed and continues to change in our understanding of the causes of troubling behaviors or emotions in children and adults. We now know that children or adults with mental retardation and individuals who are unable to communicate verbally can have emotional problems or mental illnesses. And autism is now considered to be a developmental disability that is present at birth (see "Medication and Autism," page 52).

#### The role of stress

In stressful circumstances, all individuals may experience less self-control and may behave in less mature ways. Individuals with mental retardation and/or communication difficulties may have particular difficulty coping with stress. For example, a child who is unable to express his or her feelings and needs with understandable speech may become increasingly frustrated and angry.

In fact, individuals with mental retardation and/or communication difficulties may be more susceptible to certain emotional and behavioral disorders than other individuals. For example, some children with disabilities may find school particularly stressful. Some children with mild to moderate mental retardation who are placed in regular classrooms may recognize that they are intellectually



### ANDY

At 10, Andy entered the psychiatric unit of a local hospital for treatment of a bipolar disorder. Hospital staffers snapped this identification photo on the night he was admitted.

behind others of the same age and may experience feelings of failure, particularly if they are not provided with appropriate supports. Others may suffer low self-esteem if they are placed in a specialized educational setting they feel is beneath their capabilities.

#### Challenges in assessment

When children, with or without disabilities, behave in troubling ways, a comprehensive assessment by a mental health team can be helpful.

While every child has ups and downs, intervention may be needed if something that looks totally out of character is observed—for example, if a child who is usually well-behaved suddenly becomes hyperactive and elated, or if a typically happy child appears depressed and morose. A marked change in sleep patterns may also reflect an underlying disorder.

Mental illness is not always the correct explanation for troubling behavior, however. A first step is to determine whether or not a specific behavior is appropriate for the child's level of intellectual and emotional development. For example, an adolescent who regularly talks out loud to himself might be considered "odd." However, such behavior may be "appropriate" for a 14-year-old with mild to moderate mental retardation. Without considering the child's developmental level, the behavior might incorrectly suggest a psychosis, such as schizophrenia.

#### Steps toward accurate diagnosis

To obtain an accurate diagnosis, profes-

sionals and parents should first try to identify the source(s) of the troubling behavior(s). This process includes an investigation of possible physical origins or links to a specific developmental disability. For example, symptoms of hypothyroidism—a deficiency in the functioning of the thyroid gland—can be mistakenly interpreted as depression; both have similar clinical pictures, including chronic sleepiness and lack of energy.

It is also important that the clinical team-including parents, educators and mental health professionals—examine the child's day-to-day environment. Since children participate in different activities in different settings and are supervised by a variety of caregivers, the team can try to determine whether inappropriate behavior(s) are reactions to specific events, environments or individuals, or whether these behaviors result from an internal source that causes the behavior(s) in every environment. When the same behavioral difficulties occur in each setting, the source is probably within the child and can be considered a psychological problem or mental illness.

#### Biochemical and genetic clues

Current research indicates that many mental illnesses are related to an imbalance of neurotransmitters—chemical messengers in the brain. For example, studies show that low levels of the neurotransmitters serotonin and norepinephrine may contribute to depression.

Family histories can reveal a genetic vulnerability to certain mental illnesses. For example, unipolar depression-depression without a manic phase-is far more common in children whose biological parents also had unipolar depression, even if those children were raised by adoptive parents. A genetic relationship can be found in manic-depressive (or bipolar) disorders as well. Andy Ayres' younger brother was subsequently diagnosed with a manicdepressive disorder,

and there is a history of the disorder in the families of both parents.

The significance of biological factors does not mean medications can "cure" mental illnesses in the same way an antibiotic might cure a disease like pneumonia. Experts stress that medications are most effective when used as part of a treatment program that may include behavior management (attempts to teach more appropriate behaviors through the systematic use of rewards) and/or psychotherapy (a form of treatment that involves play and/or discussions between a child and therapist to bring about a change in the child's feelings and behaviors).

#### Medication and assessment

A specific, diagnosable mental illness is not always clear even after a thorough clinical assessment. In those cases, diagnosis can be a process of elimination.

Trials with medication used to treat specific symptoms can sometimes help to clarify a diagnosis. For example, it can be difficult to determine whether depression is a unipolar depression or part of a bipolar (manic-depressive) condition. Treatment with anti-depressant medications can help clinicians make this distinction, because such medications can trigger manic behaviors when administered to an individual in the depressive phase of a bipolar disorder.

#### Common psychoactive medication

There are several broad categories of psychoactive (or "mind-affecting") medications. These medications should be prescribed only by physicians who are experienced in their use. Ideally, they should be prescribed by a psychiatrist (a physician with specialty training) who also has experience treating individuals with disabilities. Below, brand names are listed first; generic chemical names follow in parentheses. •Stimulant medications, such as



Thirteen-year-old Andy (right) clowns around with younger brother Chris, 11, outside the residential school Andy now attends.

continued on page 52

Dexedrine (dextroam-

#### **Medication and Autism**

Although autism is characterized by a variety of unusual behaviors, it is considered a developmental disability rather than a mental illness, because it can be linked to a structural irregularity in the brain (approximately 25 percent of children with autism also have seizures). In addition, autism is usually diagnosed in infancy or early childhood, earlier than most mental illnesses.

#### Typical behaviors

Unusual behaviors typically seen in autism include:

- Inability to form normal intimate/social relationships: Infants or toddlers with autism
  often resist affection from or are indifferent to parents or caregivers. As they get older, most
  children with autism have difficulties related to social interaction. Some seem to desire
  friendships but are unable to initiate such relationships appropriately.
- Unusual relationship with objects: A child with autism may show either avoidance of or intense attraction toward particular objects, such as pieces of string, wheels on toy cars, rocks or paper clips. Some children with autism are extraordinarily fascinated with moving objects, such as fans.
- Repetitive or "stereotyped "behaviors: Children with autism may engage in repetitive, seemingly uncontrolled movements such as hair-pulling, arm-flapping, head-banging or continually repeating specific vocalizations (sounds or words). Some people consider these behaviors "tics" (involuntary, repetitive movement of a muscle or small muscle group).

Some children with autism engage in "obsessive-compulsive" behavior, turning every-day tasks into elaborate rituals that must be performed in a precise manner. For example, a child with autism may insist on taking exactly seven steps from his or her bed to the door.

Likewise, many children with autism become distressed when their environment is changed in any way. A child may become extremely upset if a particular stuffed animal is moved even slightly from its usual place.

- Hyperactivity: About half of all children with autism, especially children younger than eight, may be classified as hyperactive or as having attention deficit hyperactivity disorder (ADHD).
- Communication difficulties: Some children with autism are unable to speak, or if able, may use words in an unusual manner—perhaps repeating a single word over and over, often in situations when the word seems irrelevant. Often, children with autism also have considerable difficulty comprehending language.

#### Treatment with medication

Some typical behaviors of children and adults with autism appear similar to symptoms of mental illness seen in people who do not have autism or other developmental disabilities. As a result, some people have tried—with varying degrees of success—to decrease or eliminate some typical "autistic behaviors" with the same medications used to treat similar symptoms in individuals who are not autistic.

Research has shown that Trexan (naltrexone) increases sociability. Researchers at Children's Hospital of Pittsburgh have also reported that use of Trexan led to increased control of impulsivity and hyperactivity in younger children with autism. Prozac (fluoxetine) may also increase sociability, but like Trexan, is still considered an experimental treatment.

Some medications seem to hold promise for treating certain stereotyped behaviors. For example, Haldol (haloperidol) may help control the frequency and intensity of tics, and Naltrexone may reduce self-injurious behavior like hair-pulling and head-banging.

Many of the same medications used to treat "obsessive-compulsive" behavior in children and adults without disabilities—Prozac, Zoloft (sertraline) and Luvox (fluvoxamine maleate)—may also be used in children with autism. Unfortunately, these medications often do not work the same way for individuals with autism. At lower doses, they may appear somewhat effective. But increasing dosages to the same levels normally used in children without autism can produce adverse side effects, including irritability and aggressive behavior. With these relatively new medications, it is essential that the team be aware of the potential for toxic reations.

Hyperactivity in children with autism may be treated with the same stimulant medications used by children without autism. These include Ritalin, Dexedrine and Cylert. Children with autism, however, sometimes respond adversely to these medications; in some cases, their behavior deteriorates rather than improves.

Medication will be only one component of a team-based treatment plan for a child with autism. A specialized educational program and appropriate therapies will also be part of a comprehensive treatment program.

Some parents and professionals believe treatment with nutritional supplements can be effective in treating some autistic behaviors. However, the experts consulted for this article do not recommend this approach.

continued from page 51

phetamine sulfate), Ritalin (methylphenidate hydrochloride) or Cylert (pemoline), can be useful as part of the treatment for attention deficit hyperactivity disorder (ADHD).

- Anti-depressants may be used in the treatment of serious unipolar depression, school phobia (intense fear in young children of going to school), ADHD, and some serious anxiety disorders, ranging from vague, chronic unease to sudden panic attacks during which an individual may feel heart palpitations, choking sensations, dizziness and abdominal pain.
- •Antipsychotic medications, such as Haldol (haloperidol), Stelazine (trifluoperazine) or Thorazine (chlorpromazine) may be prescribed for the individual with a psychosis—a break with reality that can involve hallucinations (perceiving sights and sounds that do not exist) or delusional thinking (believing in scenarios or identities that have no basis in reality, such as believing that one is God or Superman).
- •Lithium and Tegretol (carbamazepine) may be helpful in treating bipolar disorders and minimizing future manic-depressive episodes.
- •Anti-cruxiety medications may be used sho: t-term (from several days to approximately six months) for certain conditions associated with high anxiety. Their usefulness in children has not been well-studied, and their effects often seem to level off or fade with long-term, constant use.

#### Treatment issues

Medication can be an important part of a comprehensive treatment plan for some mental illnesses in children and adolescents. Ongoing evaluation and monitoring by a physician is essential. A monthly phone consultation paired with clinic visits every two to three months is adequate if the child's behavior is improving or becoming more stable. If not, more frequent visits and/or a change in medication may be required.

Parents need complete information when psychoactive medication is recommended as part of their child's treatment plan. Children and adolescents can also be included in these discussions. By asking questions such as those listed in "Questions to Ask" on page 53, children, adolescents and their parents can gain a better understanding of psychoactive medications.

Since all medications may produce



#### **Ouestions to Ask**

edication can be an important part of treatment for some mental illnesses in children and adolescents. However, parents need complete information when psychoactive medication is recommended for their child. By asking the following questions, children, adolescents and parents will gain a better understanding of psychoactive medications:

1. What is the name of the medication? Is it known by other names?

What is known about the drug's effectiveness in children with similar symptoms?

3. How will the medication help? How long before we see improvement?

4. What side effects commonly occur with use of this medication? 5. What side effects occur more rarely? What serious side effects

are possible?

6. Is this medication addictive? Can it be abused?

7. What is the recommended dosage? How often will the medication be taken? What times of day should the medicine be taken?

8. Are there any laboratory tests, such as heart function or blood tests, that need to be done before taking the medication? Will any tests need to be done while using the medication?

9. Will a psychiatrist be monitoring the child's response to the medication, making dosage changes if necessary? How often will the child's progress be assessed? And by whom?

10. Are there any other medications or foods that should be avoided

while taking the medication?

11. Are there any activities that should be avoided while taking the medication? Are precautions recommended for any other activities? 12. How long will the medication be needed? What factors will lead to a decision to stoo this medication?

13. What do we do if a problem develops—for example, if the child becomes ill, if doses are missed or if we see signs of side effects? 14. What is the cost of the medication (generic vs. brand name)? Is it covered by health insurance? What sort of financial assistance is available?

15. Do members of the school staff need to be informed about this

medication?

If, after asking these questions, parents still have other questions or doubts about treatment with medication, they can ask for a referral to another child/adolescent psychiatrist for a second opinion. Parents seeking referrals to a local child/adolescent psychiatrist may contact the American Academy of Child and Adolescent Psychiatry (AACAP), 3615 Wisconsin Ave. NW, Washington, DC 20016; (202) 966-7300.

This sidebar was adapted from "Questions to Ask about Psychoactive Medications for Children and Adolesecents," part of the FACTS FOR FAMILIES series of fact sheets from AACAP. The series includes 53 fact sheets on a variety of topics related to the mental health needs of children and adolescents. To obtain a complete list of topics, send your request, with a selfaddressed, stamped envelope, to AACAP Public Information, 3615 Wisconsin Ave. NW, Washington, DC 20016. Free copies of up to five individual fact sheets can be obtained by mailing a self-addressed, stamped envelope to the same address.

A complete set of all 53 fact sheets may be purchased for \$18 (includes postage). Make checks payable to "AACAP," and send to AACAP Public

Information, P.O. Box 96106, Washington D.C. 20090-6106.

harmful side effects of varying degrees, parents always need to ask about potential side effects. Although certain side effects may be characteristic for a specific medication, any drug can occasionally produce unique, unusual changes. Parents may want to contact the prescribing physician whenever they observe any major changes in their child's behaviorexpected or unexpected—while on medication. If side effects persist, it may be time for an alternative medication.

The Ayres have had to adjust Andy's medication on a few occasions. "At one point, the Tegretol affected Andy's liver functioning, and his white blood cell count started to fall off quite drastically," said Carter. "Lithium has been the most successful.'

Children with special health care needs may have some unique issues their parents can explore with the clinical team before initiating treatment with medications. For starters, the team should examine the potential physical side effects of certain medications in areas where the child may be especially vulnerable. For example, parents of children with heart conditions might wish to consult a cardiologist before proceeding with psychoactive medications. Some of these medications—the tricyclic antidepressants, for example—can affect the heart's rhythm, slowing and accelerating the heartbeat irregularly.

Sometimes, too, there can be an

undesired interaction between certain psychoactive medications and other medications being used for conditions related to a developmental disability. One medication might dampen the effectiveness or exacerbate the side effects of the other. Parents with children on anti-seizure medication, for instance, need to remember that certain other medications can reduce the effectiveness of the anticonvulsant, while others can exaggerate its potency to toxic (poisonous) levels.

Parents need to describe the details of their child's current medication program to their child's psychiatrist. It's also important for the other medical professionals involved to confer with the psychiatrist, with each other, and with the parents, so each has a thorough understanding of the treatment plan that can be taken into consideration when any new medication is prescribed.

#### Not a "cure"

Psychoactive medications, when used as part of a comprehensive treatment program, can offer a degree of control over mental illnesses, but "cures" are still unavailable. Andy, now 14, continues to struggle, but his parents are grateful for the progress he has made.

"Andy still has some impulsive behaviors, but I think he's feeling a lot better about himself," says his dad. EP

—Jason Rocder

Jason Roeder was an editorial intern with Exceptional Parent. He is now completing an internship at BOSTON magazine.

The following experts generously assisted with this article:

- James Leckman, M.D., Neison-Harris Professor of Child Psychiatry and Pediatrics, Child Study Center; Yale University School of Medicine, New Haven, CT.
- Edwin Mikkelsen, M.D., Associate Professor of Psychiatry, Harvard Medical School; Medical Director, Mentor Clinical Care, Boston, MA.
- Luke Tsai, M.D., Professor of Child Psychiatry and Pediatrics and Director of Developmental Disorders Clinic, University of Michigan, Ann Arbor, MI.

Some of the information in this article was adapted from:

- The Facts for Families series of fact sheets from the American Academy of Child and Adolescent Psychiatry. For more information on this series, see "Questions to Ask" above.
- Let's Talk Facts About: Childhood Disorders, a 15-page booklet produced by the American Psychiatric Association (APA). For a single free copy, write to APA, Division of Public Affairs, Dept. EPM, 1400 K St. NW, Washington, DC 20005. For information on bulk orders, call (800) 368-5777.



# **MOVE International**

#### GIVING CHILDREN INDEPENDENT MOBILITY AND CHOICES

OVE International is about people who care. About dedicated individuals who took a hard look at their past work and had the courage to call it a failure. About people who are challenged by immobility, and about the people who care about them. People like Linda Bidabe.

#### ADMITTING FAILURE

MOVE—Mobility Opportunities Via Education—began with children who had severe mental and physical disabilities and attended the Blair Learning Center in Bakersfield, California. In the early 1980s, the staff of the center decided to take a cold,



hard look at the outcomes of their efforts with these children.

The results of this evaluation were depressing: Sixty-three percent of the students who had profound disabilities and were nonambulatory were func-

tioning below the six-month level of motor skill development. These children had entered the educational system at three years of age. However, by the time they left school at age 22, many seemed to have fewer skills than when they had entered. Babies were growing into young adults with painful deformities and bleak futures. Many students had such poor head and trunk control that they could not sit unsupported; most could not feed themselves or use the toilet.

Linda Bidabe, an educator working for the Kern County Superintendent of Schools Office (which operates the Blair Center) realized that one reason for this apparent regression in skills was that the children spent most of their time reclining in bean bag chairs or strapped into wheelchairs. As they grew older and heavier, gravity became the enemy. With increasing size and weight, the children became less able to bear weight on their legs, pull up to a sitting position or take reciprocal steps. With lack of use, their limbs became less flexible and less amenable to manipulation or therapy. Over time, the children's educational program turned into custodial care; teachers and therapists had to spend so much time caring for the children's basic needs—positioning, feeding and toileting—that there was little time left to help the children learn new skills.

#### PILOT PROGRAM

A dynamic and gifted teacher, Linda refused to accept this situation as the inevitable result of severe disabilities. In the summer of 1986, Linda's office created a mobility pilot program to focus on just three skills—sitting, standing and walking. The students involved in the program were between the ages of six and 16; all had multiple disabilities. None of the children had ever walked. Only one had any speech. The program



involved integrating every aspect of the educational curriculum into a physical activity that could help teach specific motor skills. For example, during speech therapy, the children were placed in an upright stander instead of a wheelchair. During art, students would sit in chairs that had been slightly modified to provide support and prevent falls but that would encourage their back and stomach muscles to work throughout the duration of the activity.

The results of the pilot program were astounding. The teachers worked with individual children throughout the day on specific motor skills, such as sitting or standing. Within a matter of days, an individual child would progress from tolerating this activity for a few seconds, to sitting and standing for an hour or more.

Not only were the children mastering the motor skills that had been the original objectives of the program, they were also becoming more alert and interactive—laughing and making attempts to communicate with their teachers and with each other. Giving a child a means of independent mobility—and the opportunity to make choices—became the foundation for the development of additional skills.

Teachers were amazed. Parents were thrilled. It was obvious the program needed to be defined and expanded. Through a Rotary International fellowship, Linda spent a year in Australia replicating the early successes of the program and doing research to write the MOVE curriculum.



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EXCEPTIONAL PARENT / NOVEMBER 1995

#### AMBER STEENBOCK

Living a life on the move

Liver since I can remember, I have wanted to get around and go places. This might have something to do with moving being a big part of my childhood. I was born in Japan. About three months later, my parents and I moved to Colorado. There, my two younger sisters made their appearances.

Even as a very young child, I seldom allowed my physical disability (quadriplegic spastic cerebral palsy) to interfere with my perpetual goal of being on the move. After mastering the art of rolling, I found this to be a relatively fast and efficient mode of travel for my little body.

After kindergarten, we moved to Kentucky. There, I got my first motorized wheelchair. The wheelchair didn't go very fast, but I enjoyed my new freedom, and thought I was not stuff. So did my new neighborhood friends. Together, we discovered a great

new way to have fun. A jump rope was tied to my chair handle, and six or eight roller skaters were given a "highspeed" tow.

A couple of times, I even ran away from home. I packed my little toy suitcase with my favorite things and drove angrily down the sidewalk—but I always changed my mind by the time I tumed the first corner.

After eighth grade, we moved to our farm in Oregon and put down some roots.

My sisters and I attend Marshfield High School, where I am a senior.

When my physical therapist introduced me to the MOVE program at the beginning of the last school year, I



Amber Steenbock enjoys the view from her family's deck with buddies Scooter (on lap) and Rebel.

was interested. She told me that this was no ordinary program. Rather than the therapists telling me what to do, I would be in control of the cace and order in which I progressed. That sounded very cool. So, we went to work.

I wasn't very impressed in the beginning. Learning to balance in a regular chair was hard work. It took a long time and it wasn't much fun. But after I mastered that skill, things started moving faster. Next, I worked on "prompted" standing for three minutes, and then prompted walking, supported from the front or the rear.

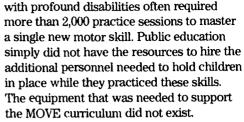
In December, I met a brilliant, fun and incredibly understanding woman named Linda Bidabe, the creator of MOVE. Linda brought me a Rifton Gait Trainer. I stood there for a minute, feeling an awesome sense of control. This was going to be the first time I would walk under my own power. I took off across that cafeteria, and I've never looked back.

The Gait Trainer is a walker with adjustable, removable prompts. Already, my "training wheels" have been removed; next I'll lose the seat.

MOVE has opened doors for me. Transfers are easier. I eat lunch in a regular chair. I walk the halls after school and chat with friends. I am able to "dance." Almost every day, I gain confidence, and am surprised by new or better abilities.

-Amber M. Steenbock

Amber M. Steenbock, 17, lives with her sisters Erin, 16, and Audrey, 14, and parents, Mark and Deborah, on a family farm in Coos Bay, Oregon. Amber loves reading, writing and using her computer. She also enjoys working with small children; one of her goals is to become an elementary or pre-school teacher.



In the beginning, Linda and the staff of the Blair Center created their own equipmentusing little more than old bicycle parts and imagination. Then, in 1990, Linda asked the Hutterian Brethren, members of a Christian community who operate Rifton Equipment, if they would like to work with the Kern County Superintendent of Schools to meet the unique needs of this program. The equipment had to be versatile enough to serve a variety of students with varying levels of proficiency, yet sturdy enough to be passed down from class to class as children progressed through the program. The equipment needed to support children with the most severe disabilities, yet that support had to be progressively removable as students gained strength and skills.

As a result of this collaboration, Rifton designed and created several key pieces of equipment—the Mobile Prone Stander, the Universal Chair Frame and the Gait Trainer. Each piece of equipment uses a series of "prompts"—belts or straps—that provide support to different parts of the body and can be gradually removed as a child develops skill and confidence.

#### THE CURRICULUM IN ACTION

MOVE takes a practical, common-sense approach to teaching children to sit, stand and walk.

For years, many doctors, therapists and teachers have believed that in order to walk, children must first learn to push up and crawl. The natural inclination of adults is to begin teaching where children start failing. Unfortunately, this approach did not work well for children with the most severe disabilities. As children worked on skills like crawling or rolling, they grew into adults who were still working on the same skills.

MOVE turned that model on its head. Instead of using a "bottom-up" model based on typical infant development, Linda began by doing a task analysis of the skills the children would need to lead functional, dignified lives—skills like bathing independently, feeding themselves and using the bathroom.



#### MARKUS SMITH Working toward a dream

Tarkus' physical therapist, Darron Veh, called me in October of 1994. He wanted to "try something different" with my son. Markus is 10 years old and has cerebral palsy. We had "tried" many different things to improve his motor abilities, but Markus had made little progress in the last several years. Markus could stand in a prone stander, but hated it. He could wheel himself slowly and erratically in his wheelchair, but required assistance to travel any distance. His poor vision made motorized mobility risky. What type of experiment were we going to subject Markus to this time?

Darron Introduced us to MOVE and the Gait Trainer and Mobile Stander. Markus loved the stander and was immediately able to wheel himself around in an upright position. Markus then tried the Gait Trainer. He struggled, but couldn't quite get it moving. As a team, we discussed which piece of equipment Markus should work with. We decided to work with the Gait Trainer because it would provide more room for improvement.

Markus initially required every prompt on the Gait Trainer and assistance to make it move. These struggles in the school hallways produced benefits far beyond the physical. Markus' schoolmates stopped to encourage him. A class of eighth graders gave him a spontaneous ovation. Teachers and students encouraged Markus and applauded his



every little success. His self confidence began to grow.

A year ago, Markus told a doctor, "My greatest hope is to walk someday." Ho was now taking his first steps toward this dream.

After just four months, Markus is able to walk 30 to 40 minutes a day in his Galt Trainer, for distances of up to a half a mile. He now requires only the forearm supports and one leg prompt. He still has trouble controlling his direction, but the power is all his.

Markus has moved out of a wheelchair desk, and into a "regular" desk. He said, "I love having a desk like the other

kids. I can get my own books and pencils and that other stuff." Even Markus' wheeled mobility has improved. His wheelchair speed has tripled, and he now wheels himself around the school completely independently.

My husband, Michael, has always felt Markus could walk if we could find the right equipment to give him the support he needed. We finally found the equipment and the approach. We look forward, with anticipation, to seeing what Markus can accomplish next.

-Gilda Smith, with Darron D. Veh

Markus Smith is a third grade student at Nickerson Elementary School in Nickerson, Kansas.

Darron D. Veh, P. T., is a physical therapist with Reno County Education Cooperative, which provides special education services to Nickerson Elementary School students.

Instead of starting at the point where a child begins to fail, the MOVE curriculum starts at the point where he or she begins to succeed. MOVE starts with real life skills.

Upon entering MOVE, a child is assessed starting at the *highest* skill level and moving *down* to the first level at which he or she demonstrates proficiency. If, with support, a child can bear weight and move his or her legs reciprocally, why work on the skill of crawling? With continued practice and the application of MOVE principles, many can learn independent movement.

#### MOVE GOES INTERNATIONAL

The success of MOVE has been phenomenal. The curriculum has been translated into seven languages, and training workshops are conducted throughout the United States and Europe. Today, MOVE International, a not-for-profit organization, is supplying information about the MOVE program to people in all parts of the world.

For more information, contact: MOVE International, City Center, 1300 17th St., Bakersfield, CA 93301; (800) 636-4560 (voice).

#### SIMON THORPE

Hard work leads to greater independence

In 1993, 11-year-old Simon Thorpe received a McDonald's Child Of Achievement Award for sitting on a standard chair at a table and feeding himself. For Simon, these "simple" tasks represented a major achievement.

Simon was born with profound learning and physical disabilities—including difficulties in moving and controlling all four limbs. His family was determined that Simon should live as full and active a life as possible. Together, the family worked to encourage Simon to move.

Simon Thorpe received a 1993 McDonald's Child of Achievement Award from British breaststroke champion Nick Gillingham and British television star Trudi Goodwin.

in 1984, Simon began to receive home-based physical therapy. At five, he began to attend Gorse Bank School in Chadderon, England, a special school for children with learning difficulties, where therapists, teachers and parents work closely together.

By 1992, Simon was able to sit in fully supported seating and could tolerate being placed upright in a standing frame. However, he was unable to feed himself, sit on a standard classroom chair or walk.

in June 1992, with the backing of school officials, the physical therapy department introduced MOVE. Simon's participation required teamwork from parents, teachers and therapists; but above all, it required hard work from Simon.

After one year, Simon was able to sit on a standard chair without support and feed himself. Following major surgery to his legs, Simon is now learning to walk.

—P. Norbury

Mrs. P. Norbury, M.C.S.P., S.R.P., is supervising physiotherapist of the Learning Difficulty Services department at Gorse Bank School in Chadderton, England.





to his parents, teachers, M.O.V.E.* and Rifton Equipment, Duane is making real progress. The M.O.V.E.* curriculum teaches standing, walking, and functional sitting skills to children with disabilities. Working in partnership with M.O.V.E.* founder Linda Bidabe, Rifton has developed a complete line of equipment to support the M.O.V.E.* program.

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### Role Models

### **James Meadours**

"Self-advocacy makes me feel good about myself."

Jomes Richard Meadours, 28, is a paid VISTA volunteer working for the Tulsa Arc in Tulsa, Oklahoma. In this position, Meadours, who has mental retardation, works with People First, a self-advocacy organization. He helps to set up new self-advocacy groups and to support existing groups for people with developmental disabilities.

In September 1995, James was a featured speaker at the National Collabor ative Academy on Mental Retardation sponsored by the President's Committee on Mental Retardation. This article is adapted from the speech he prepared for that event.

People with mental retardation and developmental disabilities have come a long way. I remember five years ago when I joined the board at the Tulsa Arc. It was my first time to serve on a board of any kind. Inside of me, I wondered if I was going to do well or if I would fail.

At first, I did not understand my role as a board member, but I grew as the organization grew. When I started serving on the board, the center had only three staff members. Now we have 15 staff members working across the state,

and I am one of them. Back then, I did not imagine myself doing this job today.

#### Duck, duck, goose

I remember when I was a child. It was hard to make friends. Kids made fun of me and teased me.

School was a challenge, too. When I was in fifth grade, they put me in a gym class with second-graders. That made me feel left out. In the second-grade gym class they played that little kids' game called "duck, duck, goose." The fifth grade gym class played flag football. I went home and told my mother. The next day she called the school to complain. Afterwards the teacher was angry with me because he thought the second-grade class was right for me.

It wasn't until high school that I was able to challenge myself. I took regular classes. It was hard but at least I tried. In the eleventh grade I got on the honor roll at high school. I really appreciated my teachers' support. I wish everyone could be in regular classes.

#### **Transitions**

The hardest part of leaving high school or an institution is having the ability to make something good for yourself. We need help to find jobs in the community instead of in sheltered workshops. We need better transition support. I see a lot of people get stuck in corners and never have a chance to work at a real job. It's better if you let us make mistakes in the so-called "real world."

It is important for us to have good support and real friends. We don't want paid staff to take of care of us all the time. I was in a workshop for about three years before leaving high school; I worked during the summer months.

At the time, I thought the workshop job was okay.

After high school, I moved to a group home. At the time, I thought it would be great to get out of my stepmother's hair, and my dad's hair, too. But it was hard for me. I was the only person in my group home who had never lived in a institution. I felt my family fading away from me. I felt alone.

#### Making friends

I was the only Catholic at our group home. One day I saw an announcement in the church bulletin. It talked about a dance for people who are 18 years old to "40-something."

I wanted to go, but I was scared. First of all, I did not know what they meant by "40-something." Also, I did not know what they would say about me living in a group home or if they would want a person with mental

retardation coming to the party.

But I went anyway, and I really enjoyed myself. I made friends at the party—like my best friend, Matthew, and his girlfriend, Mary. Now Matthew and Mary are married and have a little boy named Tommy.

Some of my new friends were on the church's softball team. They invited me to watch them play softball on Saturday after the party, but I couldn't go because I had to go to the workshop. The next week, I saw my new friends after church and they gave me a ride to the game. A year later, I started playing softball with them. Now I have been playing softball for seven years.

#### Living independently

Meanwhile, there were a lot of changes at the group home. They got a new executive director, and there were a lot of new rules. For example, residents had to take a test to earn a key to the home.

In 1990, I had a meeting with staff members and my continued on page 61



Eighteen-month-old James spends an affectionate moment with his mother, Ruth Ann Meadours, and infant brother, Joe.



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110

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NOVEMBER 1995 / EXCEPTIONAL PARENT • 59



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573

continued from page 58

stepmother and father to discuss my goals. I said that one of my goals was to move out of the group home. The staff told my parents I should wait until I was 30 years old.

Later, I was talking to my friends, Matthew and Mary and some others, while we watched the Super Bowl. I told them I wanted to move out of the group home.

I thought they would tell me I should stay at the group home. Instead they asked if I was free on Saturday.

I told them, "Yes, I am."

That Saturday, they helped me look for an apartment. We looked at a lot of apartments, and the last place we saw seemed like a good match for me.

The staff people at the group home called my stepmother and father. My parents questioned me about my plans. I stood tall and told them I was ready to live independently. Three weeks later, my friends helped me move into my new place.

I decided to play a joke on my friends. I called and left a message on their answering machine saying I burnt down the kitchen after my first night's stay in my own apartment.

I still enjoy living independently. I get support from People First, Best Buddies (a group that pairs people with and without disabilities) and other programs.



James (right) enjoys Christmas dinner with Aunt Sandy (left) and Cousin Lara (center).

#### Becoming a self-advocate

Everyone should try to be an advocate for someone. Even be an advocate for yourself! Sometimes self-advocacy is hard. Some people do not take us serious when we say things to try to make our lives better.

I started attending the People First group in Tulsa in 1988. My only reason for going continued on page 6.



James saved a special Christmas hug for his favorite uncle, Paul Bankies.

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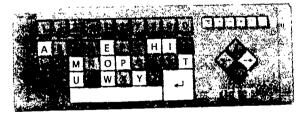
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continued from page 61

to that first meeting was to find out how to change the address on my voting card after moving to the group home. I just wonder sometimes—what if I didn't happen to change my voting card? I probably would not be involved in People First or belong to other groups helping my peers. I probably would still live in a group home and work at a workshop. I probably would have done nothing to better myself.

I have really enjoyed serving as a self-advocate with many different groups. I share my experiences as a person with mental retardation. Other people can learn from my experiences. I have learned a lot, too. It makes me feel good about myself.

#### "Listen to us!"

Last April, when the President's Committee on Mental Retardation asked me to come to Washington, DC, I felt that I would not only represent myself, but all my peers from Oklahoma. One close friend told me that professionals in the field of mental retardation would start asking me to



In April 1994, James traveled to Washington, DC to attend The National Reform Agenda and People with Mental Retardation: Putting People First, a meeting sponsored by the President's Committee on Mental Retardation. Before his participation on a panel of self-advocates, James chatted with Donna Shalala, Secretary of the U.S. Department of Health and Human Services, and Chair of the President's Committee.

speak all over the country. That made me a little nervous. My friend told me, "You feel like you need to know all the answers, but you don't. You just need to be yourself and tell how you really feel about things."

This is how I really feel: My dream is to see equal rights for people with mental retardation. I know many parents and professionals share this vision. People with mental retardation can help make this vision a reality. Listen to us. If you say something that might be over our heads, ask questions to make sure we understand. If we don't understand at first, use words we can understand so we can share information. Help us participate and give us support when we need it.

One of my favorite quotes is by Goethe. The quote is about the power of expectations, and it goes like this: "If you treat an individual as he is, he will stay as he is. But if you treat him as if he were what he ought to be and could be, he will become what he ought to be and could be."

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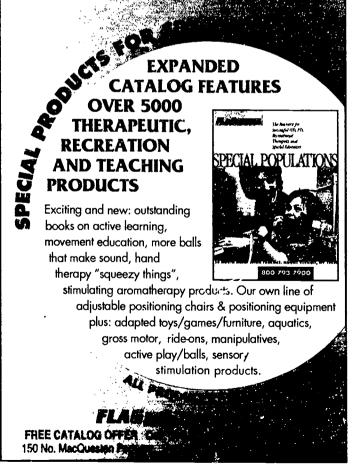
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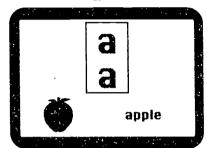
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State U. of NY, Farmingdale, NY

Joey Thomas

- U. of South Carolina, Columbia, SC

These students will join six other CHAIRSCHOLARS enrolled in schools throughout the U.S. - Best wishes to them all!!!

The trustees thank all of you for helping these courageous young men and women pursue their dreams with your kind help.

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# ASK THE DOCTOR

by David Hirsch, M.D.

## **Feeding Aversion**

My daughter is now two and a half years old. She was born at 28 weeks gestation and spent almost two months in the hospital requiring ventilation, oxygen and total peripheral nutrition (TPN), meaning all required nutrients were given intravenously. Before she was able to nipple feed, she was given formula through nasogastric feedings (in which a plastic tube was passed through her nose and esophagus, and into her stomach). She has one of the more common neurological complications of prematurity, spastic diplegia, a form of cerebral palsy resulting in spasticity or severe increased tone typically involving the lower extremities. She uses AFOs (ankle-foot orthotics or braces) and receives physical and speech therapy. Her developmental skills are only slightly delayed.

My concern is with what her speech therapist and pediatrician agree is a feeding aversion. It seems to be getting worse. She has not gained much weight in the last six months. She will take small amounts of milk from a bottle, but little else without a battle. Feedings take more than an hour, and I have to fight to get every spoonful into her. At the end of the meal, we are both frustrated. Now her pediatrician and I are considering a gastrostomy feeding tube to allow her to get adequate calories and fluids without the heartache. Do you have

In this column, David
Hirsch, M.D., a pediatrician
and member of EXCEPIONAL
PARENT'S Editorial Advisory
Board, answers questions
from readers. Dr. Hirsch is a
partner in Phoenix
Paciatrics, Ltd. in Phoenix,
Arizona. He specializes in
treating children with devel-

epmental disabilities and chronic illnesses.

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals.

Mention of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, Exceptional Papers, 200 Harvard Street, Suite 303, no. MA 02146-5005, (617) 730-8742 (Fax).

any thoughts about this problem? Is it very common?

This is a difficult situation for 🚹 the whole family. I have seen a number of children with similar problems who have been very sick either as newborns (usually with complications of prematurity) or have been very ill in the first year of life. I assume that your daughter's physicians have ruled out any physiological problem such as reflux (the abnormal backflow of stomach contents up the esophagus), recurrent aspiration (in which solids or fluids, usually stomach contents or food in the process of being swallowed, end up in the respiratory tract-usually the lungsinstead of in the digestive system), chronic abdominal pain, constipation or any type of swallowing disorder or other disorder of the central nervous system (brain and spinal cord) that may be responsible for her apparent feeding aversion.

If a physiological problem has been ruled out, your daughter may have a form of "conditioned taste avoidance learning." This phenomena, which sounds more complicated than it is, has been extensively described in animals, but also in older children and adults. In the case of infants and young children who were sick as newborns, it is thought to be a type of "phobia," a persistent abnormal dread or fear, often resulting in an aversion, brought on by one or more bad experiences. An example of a "bad experience" in this context would be significant vomiting or abdominal pain that may have occurred with oral feedings in the newborn period. The tastes or smells that occurred with the "bad" experience(s) remain a "stimulus," and a feeding aversion is the "response."

Unfortunately, since there often is not much variety in a young child's diet, just about any similar food or feeding e "perience later en can be the stimulus that brings on a feeding aversion.

Try offering a greater variety of foods that can supply the nutrition your daughter needs (you may want to consult a dietitian/nutritionist). Limit mealtimes to about 30–40 minutes, but not less than 20 minutes. If she likes milk, try a caloric supplement such as Instant Breakfast or a specialty formula, such as Pediasure, but use a cup she can handle. Her bottle may be comforting to her, but at her age and developmental level she should be using a cup.

Enlist other people to give her occasional meals. This will give you a break and the chance to see different feeding techniques (or styles) that may work well with your daughter. Try to avoid distractions during mealtime.

Stick with it. Try not to become frustrated, because your daughter will sense your frustration and become more anxious herself. You may have to consult a pediatrician who has experience in behavioral disorders (or even a psychologist) to give you more help and direction, but given enough pleasant meals and exposure to a wider variety of foods, your daughter's food aversion should resolve itself in time.

On occasion, if a child's health would be jeopardized by inadequate caloric and fluid intake, I have found it necessary to utilize nasogastric or gastrostomy feedings as a supplement, often by using a pump overnight. If this is done, however, I always recommend turning the feeding pump off early enough that child will feel "hungry" for breakfast. Check with your daughter's pediatrician about trying some of these ideas first, certainly before placing a gastrostomy tube. If the feeding aversion does not resolve itself in time-and the length of time you give it should depend on your daughter's clinical conditionthen gastrostomy or nasogastric feedings should be utilized. Even so, you should continue oral feedings and try to resolve the feeding aversion so she can take her feedings orally with enjoyment. **EP** 

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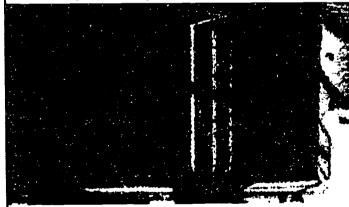
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# **HEALTH INSURANCE TROUBLESHOOTER**

by Richard Epstein

### **Coverage for Special Formulas**

Our four-year-old daughter has Opitz syndrome, Turner syndrome and a multitude of medical problems. She has never eaten food; she has always been on a special formula.

Since the age of 10 months, she has been fed by gastrostomy-tube. Our private insurer covered the pump and home care supplies, but not the formula. The company told us they never pay for "nutritional or dietary supplements." We contended that this formula is in no way a "supplement"—in fact, it is the only nutrient that keeps our daughter alive—but the insurer would not pay for the formula.

We're still with the same insurance company, but we've changed policies. Once more, I tried to get the formula covered, only to be told again that they never pay for it. I asked the company why they pay for home IVs but not formulas, since both help keep people alive. Their response was to ask if my daughter could be placed on an IV!

After the first few years of paying for our daughter's formula, we were very much in debt. Then we applied for Medicaid for her. Once she qualified, Medicaid covered her formula and has done so ever since.

We pay for our private insurance policy through my husband's employment. We do not want Medicaid to pay for our daughter's extremely expensive formula. We believe our private insurer, our *primary* insurer, should pay for this formula.

I believe that Medicaid monies should go to people without any other insurance. I am appalled that approximately \$21,000 of taxpayers money is spent on my daughter's formula every year. Representatives of our private insurance company do not understand this reasoning; they seem to think we should not be bothering them since Medicaid is covering the formula.

This battle will be tough, but we

feel we are doing the right thing. I've written to our senator, and I've filed a complaint with our state insurance commission. What other steps can I take to change the rules and regulations?

This battle will be tough, but it will also be worthwhile. Many people with children who require special formulas on a daily basis may not be able to qualify for Medicaid. As you know, the economic burden of paying for formula can be difficult to bear. In addition, the government plans to reduce spending for the Medicaid program.

Although you've filed a complaint with the state insurance commission, they are unlikely to deal with this issue. State insurance commissions have the power to require an insurer to follow existing regulations, but they do not generally issue new rules.

The state legislature, however, has the authority to pass laws requiring insurers to pay for specific treatments. Over the last few years, a number of states have considered, and in some cases enacted, new laws requiring private insurers to pay for everything from routine medical tests, to diabetes related supplies and equipment, to bone-marrow treatments.

Some states have even passed laws requiring private insurers to cover certain formulas for children with metabolic disorders. Your state legislature may consider holding hearings on the possibility of enacting new legislation that would require private insurers to cover all formulas for which Medicaid has agreed to provide coverage.

The best way to work toward that goal is through a parents' group. Precedents exist; parents have been instrumental in drafting and passing laws that address these issues. For example, in January 1994, the Massachusetts legislature passed a law requiring private insurance companies to cover formulas necessary for

the treatment of phenylketonuria (PKU) and similar metabolic disorders. Prior to the passage of this law, Massachusetts parents of children with PKU had contended with the same insurance problems you face-insurers who denied claims on the basis that formulas are food, not medicine. When these parents became frustrated enough to take on the state government, they obtained the help of PKU professionals and a legislative aide to draft a bill for a law requiring private insurers to cover both formulas and special low-protein foods. The bill also prohibited companies from setting an age limit for coverage, and it incorporated all amino acid and organic acid disorders, not just PKU. Key strategies for getting the bill passed included testifying before the joint House-Senate Committee on Insurance, sending out information packets to senators and representatives and seeking letters of endorsement from various groups.

You may want to contact parents' groups in your area to see if they're interested in working on this issue. If not, you might consider organizing your own group. Let me know what happens. **EP** 

EDITOR'S NOTE: We obtained information about PKU-related laws from NATIONAL PKU NEWS, a newsletter published three times a year. To subscribe, send \$14 to NATIONAL PKU NEWS, 6869 Woodlawn Ave., NE #116, Seattle, WA 98115-5469.

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at Exceptional PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

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a specific health insurance claim, please
include copies of any materials you've
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(Please, don't send originals!) Inchude your
address and phone number. Only your initials and state will be published. It is not possible to respond to letters individue in







# **CONNECTIONS**

The Newsletter of the National Center for Youth with Disabilities

# Students Learn (and Teach) Self-Advocacy

A group of high school students with a variety of disabilities got together with their teachers, Barb Vallejo and Sheryl Evelo, at South High School in Minneapolis, Minnesota, just about a year ago to talk about what it means to be a self-advocate. Does it mean going to the state legislature and lobbying for change? Maybe. But for these young people, selfadvocacy is closer to home.

"You have to let the teacher know that you want to learn, that you want to do the work so that the teacher doesn't think you don't want to do the work," Demont Harris says. If you don't speak up for yourself, "You're just going to be a lost soul in the classroom."

For Krista Smith, now a student at a local community college, self-advocacy includes asking for help with problems. "There are a lot of college students out there who are 40 or 30 or 20 years old who don't even speak up for themselves,

don't even ask questions. I've learned that it is really easy to do and it is really important to do because, if you don't ask questions or stand up for yourself, you're not going to get anywhere."

#### Youth Define Self-Advocacy

As these young people discussed the need to take control of their futures, the need to stick up for themselves, they developed a definition of self-advocacy:

"Self-advocacy is speaking and acting on behalf of your own rights," the students agreed. "It is the best kind of advocacy because no one knows better than you what your needs are. It's about making decisions that affect your daily lives from choosing your friends, what to study in school, what relationships to have, and what kind of job you want."

With that definition firmly in hand, they identified how they learned their advocacy skills and when, where and with whom they must advocate. With some funding from The Minnesota Transition Systems Improvement Initiative, Interagency Office on Transition Services, and assistance from their teachers and school staff, this group of special education high school students put together a video, "Self-Advocacy: Taking Charge," as an effort to

help others learn what they have learned.

They recognized that many of the decisions made at IEP (individual educational plan) meetings can have a profound effect on their lives—both their daily lives and their future lives.

One student explains that, even though they talked about selfadvocacy at IEP

> Self-Advocacy Turn to page 72





584

Self-Advocacy
From page 71

meetings, it took him a couple of IEP meetings to actually say something. Then he realized that the reason why they are making the decisions is because, "I'm not saying anything. That's when I

started speaking up for myself." That's when George Lewis learned that he could make many of the IEP decisions for himself.

"At my IEP, it helped writing my goals and letting them know what I wanted, what I think," Chantilly Lynch says.



When I walked into Barb Vallejo's high school classroom last spring, I couldn't tell who had an IEP and who did not. I hesitated a liftle and wondered how will I identify those young people who most capture my interest and imagination: adolescents with chronic illness or disability. Vallejo's students made it easy.

One young man talked about his learning disability. "You know, when I started junior high, I began having real problems. I would do the math homework but couldn't find the paper. Or I couldn't remember if I completed the assignment at all. I'd confuse one class with another." This glib, attractive high school junior could articulate his frustration. When the semester ended and he would clean his locker, he'd find all the work he'd thought he'd lost. The situation only got worse and, by high school, he was way behind his peers, feeling "dumb" and hating school.

Today, he can explain his disability to his teachers. He can tell them what accommodations he needs. "You see, each day we list out each class on this paper. The teacher writes out the assignment I have to do in class or at home. And then we organize the work." At the end of the day, Vallejo or a colleague helps him sort through the books and papers and organizes again. This self-advocate will succeed because he understands his needs and can ask for help.

Each time I meet a young person with a disability who is enthusiastic about life and feeling in control, I am certain someone has taken the time to help that youth to become a self-advocate. As parents, as teachers, as doctors and providers, our goal should be helping to build the capacity of youth with disabilities to speak out for themselves.

The story, "Speak Out: Students Learn (and Teach) Self-Advocacy," shows how one group of students learned these skills and applied them to their everyday lives. We've also provided a summary of some of the presentations made at the Great Lakes Society for Adolescent Medicine. They provide some innovative suggestions and guidance to making a difference in your community and state. Finally, Liz Latts, Information Specialist and Director of the Resource Library, has identified two projects on self-advocacy that she finds particularly interesting.

PMR



#### **Getting the Words Out**

These teens realize that learning to advocate also means teaching others to respect personal needs. Some teachers need to understand what it means to have a disability and what accommodates different learning styles. Students at South High are learning to teach the teachers.

Brett Gilman thinks the best thing that teachers could do would be to understand that some people have a hard time speaking up for themselves. Teachers need to be patient. Others explain that teachers need to provide alternative ways to complete assignments.

In turn, each of these students can explain their disability and tell their teachers how it affects their learning. That way the teacher understands why the accommodation is necessary

Students agree that they need to advocate for themselves when they

are with their friends. When tempted to skip class or get into trouble, they admit advocating is not always easy. One student admits that sometimes it's easier to just do what they say. Other times, like when his friends skip, he just tells them he forgot about meeting them. Youth need to use a variety of advocacy strategies.

"Self advocacy is speaking and acting on behalf of your own rights. It is the best kind of advocacy because no one knows better than you what your needs are."

Even parents need advice. One student asks why his mom was always nagging him when he got in trouble. She should nag him when he is doing right.

Self-Advocacy
Turn to page 73



585

Self-Advocacy From page 72

Help turn the C+ into a B+, the B+ into an A.

"As self-advocates, we've learned to speak for ourselves when meeting with teachers, at our IEP meetings, on the job, with family and friends, and planning our future and living independently," Rosie Lindberg-Lasko, summarizes. "Our experiences are sometimes different from those of other students. We have a lot to offer and can give advice to teachers, family, and especially other students who are developing selfadvocacy skills.

or more information on self-advocacy, or for information on how to get a copy of the videotape, "Self Advocacy: Taking Charge," contact:

Transition Plus Services 807 N.E. Broadway Minneapolis, MN 55413 (612) 627-2141

or

Minnesota Transitions Systems Improvement Initiative Interagency Office on Transition Services 657 Capitol Square Building 550 Cedar St. St. Paul, MN 55101

#### Adolescents & Advocacy:

## **Professionals Play Important Roles**

When the Great Lakes Regional Chapter of The Society for Adolescent Medicine (SAM) planned their fall meeting, they decided they should visit the issue of advocacy. "Physicians and nurses, social workers and nutritionists, teachers and other providers can improve the conditions for adolescents with disabilities-indeed for all adolescents," says Nancy Okinow, President of the Great Lakes Regional Chapter of SAM.

Physicians can play a critical role in their communities. Steve Matson, M.D., from Milwaukee, Wisconsin, comes with a mission. So few physicians and providers are interested in the care of adolescents that there really are wonderful opportunities to increase services for this group of young people in the community. He provides some strategies for those who wish to provide adolescent health services:

- Mark Know the area in which you work;
- Determine the needs of the young people;
- Get to know the important people in your community;
- Persuade the movers and shakers that your idea is critical to the life of youth in your area;

- Work with the media (give talks, agree to be on the local radio show); and
- Make certain the people on your team are dreamers.

Anne Dopp, R.N., M.S.N., P.N.P., from Wisconsin, says there are opportunities for advocacy and changing policy at all levels.

Providers who currently work with youth must talk to health insurance companies, to the people in benefits; show them how continuity of care for youth can increase healthy outcomes and may reduce costs.

Call your local and state representatives regularly to tell them about youth needs. If you call regularly, your issues will become familiar and you will be able to influence how your representative thinks on youth issues.

#### Persistence Pays

Ed Ehlinger, M.D., Director of Student Health Services at the University of Minnesota, explained that he's interested in issues if they are:

- Important to the community;
- Perceived as a public health responsibility;
- Intervention is possible; and
- Outcomes are measurable.

He suggests that advocates follow the "Natural Laws of Data and Policy Development":

Policy development occurs at all levels at all times, is incremental and not linear. Data is not always sufficient for policy development and sometimes not necessary to changes in policy.

Miracles do huppen.

The National Center for Youth with
Disabilities is a program of The Society for
Adolescent Medicine and the Adolescent Health
Programs at the University of Minnesota.
Publication of Connections is supported, in part, by
project MCJ-275045 from the Maternal & Child
Health Bureau (Title V, Social Security Act), Health
Resources & Services Administration, Department
of Health & Human Services.

NCYD's mission is to improve the health and social functioning of youth with disabilities through providing technical assistance and consultation, disseminating information and increasing the coordination of services between the health care system and others. Center activities are directed at enabling youth to become full participants in their communities.





The National Resource Library brings together comprehensive sources of information related to adolescents, disability and transition to meet the needs of professionals who work with youth with disabilities as well as their parents and others invested in their success. The database contains five files:

- Bibliography
- Programs
- Training Materials
- Technical Assistance
- Health Care Reform

Entry points to the Library's files are through language and issues of individual fields. Information in the files is interdisciplinary, offering the many views that may enhance practice with adolescents and young adults with disabilities.

#### **Programs**

"Project LEAD" has focused on leadership development and inclusion of youth with disabilities in the community. Teens ages 13–18, with and without disabilities, participated in a yearly retreat to learn about legal rights and responsibilities, educational rights and self-advocacy. Social and educational activities throughout the year were used to develop leadership, promote friendships and self-esteem. Youth-oriented organizations receive training and technical assistance to make their staff, programs and facilities accessible.

For information, contact:

Project LEAD Stepping Stones Karen Newton (304) 296-0150 (800) 982-8799

or

Renie Boyle (304) 599-5**2**86

#### **Training Materials**

"No More B.S.: A Realistic Survival Guide for Disability Rights Activists." This book is written by disability rights activists. It promotes self-advocacy, the development of self-esteem and community organization as a way of fighting discrimination and securing rights for persons with disabilities. It is written in a strong "straight-shooting myth bashing tell-it-like-it-is" style. A companion booklet is available for direct service providers. Cost is \$10.00.

For information, contact: People First of Washington P.O. Box 648 Clarkston, WA 99403 (509) 758-1123 (800) 758-1123 Inquiries about NCYD may be directed to:
National Center for Youth with Disabilities
University of

Minnesota Box 721 420 Delaware St. S.E. Minneapolis, MN 55455 1-800-333-6293 612-626-2825 FAX (612) 626-2134 TTY (612) 624-3939

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& Production

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# **№** We've Got A New Home and New Address

The National Center for Youth with Disabilities has taken the digital leap! For those of you who are interested in learning more about NCYD or our sister Center, the Center for Children with Chronic Illness and Disability, you can find us on the World Wide Web. While the pages are under construction, anyone interested can dial us up using one of two http numbers:

**http://www.peds. umn.edu/Centers /ncyd** gets you to the National Center for Youth with Disabilities, interactive listings, basic information on the Center and a biblography on transition.

**http://www.peds.umn.edu/Centers/c3id** gets you to the Center for Youth with Chronic Illness and Disability, interactive e-mail listings, basic information on the Center and recent publications.



587

# **Speaking Out**

**Books and Videos About Living With Seizures** 

### Students With Seizures: A Manual for School Nurses

Designed to promote a more accepting and understanding school environment for the more than 300,000 children with seizure disorders in the United States. The first half of the manual reviews epilepsy, seizure classifications and different treatment methods. The second half focuses on the school nurse as case manager and educator: it discusses how school nurses can educate teachers and parents about epilepsy—recognition, medication effects, skills assessments.

Catalog # 148SWS 144-Page Manual \$22.46 EFA Member \$24.95 Non-Member

## School Planning for Children with Seizure Disorders

Of special interest to families in which a child with epilepsy also has a learning disability or is not doing well in school.

Describes some epilepsy-related problems that may affect learning, what kinds of service may be needed and how parents can function as full-fledged members of the school planning team.

Stresses inclusion in regular school activities. A Family Video Library presentation. (1992)

Catalog # 533SCD VHS Videocassette, 14-Minutes \$13.46 EFA Member \$14.95 Non-Member

### Seizure Disorders and the School Videos I & II

Videos show actual seizures in children, describes first aid and management in the classroom, and stresses the importance of early recognition. Fears and concerns of school personnel are addressed. Reviews how epilepsy may affect learning and discusses how the teacher can make the school experience a positive one.

### Seizure Disorders and the School I

(For use with Elementary School personnel)

Catalog # 521SD1 VHS Videocassette, 14-Minutes \$22.46 EFA Member \$24.95 Non-Member

### Seizure Disorders and the School II

(For use with Junior High and High School personnel)

Catalog # 522SD2 VHS Videocassette, 14-Minutes \$22.46 EFA Member \$24.95 Non-Member

# Speaking Out: Partners in Advocacy—Understanding the Process

What is advocacy and why is it important? This guide provides basic definitions and principles, and discusses how people can become advocates in their own right. It reviews different types of advocacy, including personal and case advocacy, systems advocacy, and legislative advocacy. (1992)

Catalog #168PAU 20-Page Guide \$5.36 EFA Member \$5.95 Non-Member

# Speaking Out: Partners in Advocacy—Tools & Resources

Provides a wealth of information and resources for individuals, families, organizations, and parent support groups interested in advocacy. Includes sample documents: letters, complaints, IEP (Individualized Education Program) and IFSP (Individualized Family Service Plan) forms and sample testimonies which families and advocates can adapt for use in their own advocacy efforts.

Catalog #171PAT 89-Page Guide \$9.86 EFA Member \$10.95 Non-Member

# Speaking Out: Partners in Advocacy—Family Action Guide

Advocacy includes: identifying an unjust situation, developing strategies and planning action to bring about change. Discusses why families must be advocates for their children. Provides a clear eight-step process to help you get started as an advocate and identifies the skills and time commitment necessary for effective advocacy. Presents examples of case advocacy and discusses opportunities for advocacy in your community. (1992)

Catalog #169PAF 50-Page Guide \$8.96 EFA Member \$9.95 Non-Member

# School Planning: A Guide for Parents of Children with Seizure Disorders

This guide describes some epilepsy-related problems that children and youth may face in the areas of academics, school achievement and social development. Suggests ways parents can take a proactive approach to ensure appropriate testing, placement and achievement of educational goals for their children. Sample IEP's included. (1994)

Catalog # 217GSP 125-Page Guide \$11.66 EFA Member \$12.95 Non-Member

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# WHAT'S HAPPENING

#### Video Focuses on Telecommunications

Independence through Telecommunications:

A Guide for Parents of Deaf and Hard of Hearing Children, an 18-minute video from Gallaudet University's Technology Assessment Program, explains how visual telecommunications technology can provide deaf and hard of hearing children with access to the telephone. The video features open captions, on-screen explanations in

video features open captions, on-screen explanations in American Sign Language (ASL) and voice narration throughout. Focusing on technologies such as TTYs, relay services, fax machines and on-line services, the video features easy-to-understand explanations and testimonials by parents of children who use telecommunications devices and services. To order, send \$5

(includes postage) to GRI Dissemination Office, Hall Memorial Building S-444, Gallaudet University, 800 Florida Ave. NE, Washington, DC 20002; (202) 651-5257 V/TTY.



Bridges To
Reading is a comprehensive kit containing information, tools and references designed to be a first source for parents of children with learning disabilities associated with reading. The kit contains eight step-by-step

booklets that answer questions about identification, testing and educational rights, along with reference guides on a variety of other topics. *Bridges to Reading* can be ordered from Parents' Educational Resource Center, 1660 S. Amphlett Blvd., Ste. 200, San Mateo, CA 94402-2508; (800) 471-9545. Cost is \$20; complimentary copies are available to those who cannot afford this amount.

#### SSI/SSDI Help

Confused about Social Security benefits? Help is just a toll-free phone call away! The Benefits Resource Network, operated by Kennedy Krieger Community Resources in Baltimore, Maryland, answers questions about Social Security benefits (Supplemental Security Income and

Social Security Disability Income) and Social Security Admin-istration work incentives. Call (800) 677-9675 (or 410/327-7122 in the Baltimore area) Monday through Friday, 9 a.m. to 5 p.m., EST.

#### Chronic Fatigue and Immune Dysfunction Syndrome

Chronic fatigue and immune dysfunction syndrome (CFTDS), also known as chronic fatigue syndrome (CFS), is an illness characterized by incapacitating fatigue, neurological problems and a constellation of symptoms that can resemble other disorders including mononucleosis, multiple sclerosis, fibromyalgia, AIDS-related complex (ARC), Lyme disease, post-polio syndrome and autoimmune diseases such as lupus. The CFIDS Association of America has put together a package focusing specifically on children's issues. The package

includes information on the physiological, psychological, educational and social aspects of CFIDS. Each package costs \$10. Contact CFIDS Association of America, P.O. Box 220398, Charlotte, NC 28222-0398; (800) 442-3437; (704) 365-9755, fax.



### CD-ROM Library of Disability Information

The Cooperative Electronic Library on Disability, newly-released on CD-ROM, contains data on products and services for people with disabilities, as well as information resources on disability. The CD-ROM is compatible with both IBM PC (DOS or Windows) and Macintosh computers. Contact Trace Center Reprint Service, Waisman Ctr., University of Wisconsin, 1500 Highland Ave., Rm. S-151, Madison, WI 53705; (608) 263-2309 (voice); (608) 263-5408 (TTY). Cost is \$27.



As PBS's criticallyacclaimed children's series, The Puzzle Place, enters its second season in January 1996, Kyle (far right, in wheelchair) will be joining the cast in an expanded role. The series, focusing on the adventures of an ensemble of puppet "kids" of diverse backgrounds and ethnicities, intro-

duced Kyle in the "Willing and Able" opiecde of its premiere season.

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DIRECTIONS

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AMERICA'S DISABILITY CHANNEL



# MEDIA



Written by 25 leading medical experts,
MEDICAL & SURGICAL CARE FOR CHILDREN WITH
DOWN SYNDROME: A GUIDE FOR PARENTS provides
in-depth, easy-to-understand information on
specific conditions that are common among
children and adults with Down syndrome.
This book is available from Exceptional
Parent Library (800/535-1910). The following
is an excerpt from chapter eight, "Ear, Nose

and Sinus Conditions of Children with Down Syndrome," by Kevin Kavanagh, M.D.:

Children with Down syndrome may have a variety of ear, nose and throat (ENT) problems. Many of these problems are easily detected and may worry parents, but they typically correct themselves as children grow older. These conditions include sinus drainage, drooling, mild blockage of the nasal airways and tongue protrusion.

Other conditions may be less apparent and commonly go unnoticed by the family. Unfortunately, these problems are often more serious. They may include hearing loss and more serious blockage of the nasal airways. When any of these conditions are detected, they should be promptly treated.

Though the above list may seem long, not all children with Down syndrome will have these conditions. If your child has one of these conditions, talk with your primary health care provider such as a nurse practitioner, pediatrician or family practitioner. They can refer you to an ENT physician if necessary. For typical ear, nose, and throat conditions, treatment for children with Down syndrome is the same as for other children. However, some circumstances that call for special considerations do exist...

#### **Sinusitis**

Sinuses are the small cavities in the cranial bone located behind the nose. They serve as air passages that open off the main nasal airway. They act like a sounding board and affect the quality of speech greatly. When sinuses become filled with fluid, as they do when there is an infection, the quality of speech changes.

Because of the relatively small size of the nasal cavities in children with Down syndrome, sinusitis (sinus infection or inflammation) is common. So, too, is drainage from the nose (runny nose), because nasal drainage is often due to infection or inflammation of the sinuses. Eight out of 10 children with Down syndrome have persistent nasal drainage. Although most children have runny noses occasionally, children with Down syndrome can have this problem much more frequently and for longer periods of time. For most children with Down syndrome, the problem decreases as they reach adulthood.

If nasal drainage is thick and yellow-green in color, this suggests a possible bacterial infection. Initial treatment may be with antibiotics. If the drainage starts up again soon after you stop giving your child antibiotics, your primary health care provider may prescribe a low-dose antibiotic to be given over a long period of time (months to years) to prevent a return of the infection. The side effects are usually minimal; however, in some children, the antibiotic can alter the bacteria that live in the GI system and result in diarrhea, allergic reactions and failure to kill the targeted bacteria.

Sometimes it is suggested that modifying your child's diet can reduce sinus infections, but there has been no scientific evidence that this works. Some allergists prescribe nutritional modifications for children who have shown an allergy to some specific food and who have persistent sinus infections.

If your child's drainage is clear, your child may have allergies. In this case, your doctor may prescribe antihistamines or decongestants. In a formal survey, six of 10 patients with Down syndrome obtained relief from drainage and other allergy symptoms when they used antihistamines or decongestants. However, those medicines make some children sleepy. In other children, they may cause increased activity. These symptoms usually go away in about two weeks. There are no studies showing that children with Down syndrome are more prone to allergies than other children.

If your doctor suspects that your child has a serious sinus infection or inflammation, he or she will usually ask for x-rays of the sinuses. In some cases the doctor may order a CT scan of the sinuses. A CT (computerized tomography) scan is a special x-ray test that gives a clearer view of the sinuses and can be helpful in making a decision about whether or not surgery is needed.

As a last resort, surgery to promote sinus drainage is an option. This should only be performed if the drainage is excessive or your child has recurrent sinusitis with fever. The most common sinus surgery involves placing a drainage hole or "window" in the sinus located in the upper jaw (maxilla). This surgery is done under general anesthesia. More extensive sinus surgery is only done as a last resort in children under the age of eight... In these young children, the sinus cavities are small, the operation is technically more difficult, and results are often unpredictable. **EP** 

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#### Coming in December...

An excerpt from Cerebral Palsy: A Complete Guide for Caregiving. This book, written by a team of experts associated with the Cerebral Palsy Program at the Alfred I. duPont Institute in Wilmington, Delaware, addresses the many complexities and uncertainties related to a diagnosis of cerebral palsy. At the same time, it provides the information parents, grandparents,

caregivers and health professionals need—everything from medical, educational and psychosocial implications of this diagnosis, to wheelchair maintenance and dental care.



591

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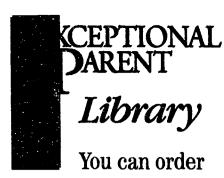
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Marilyn Lash

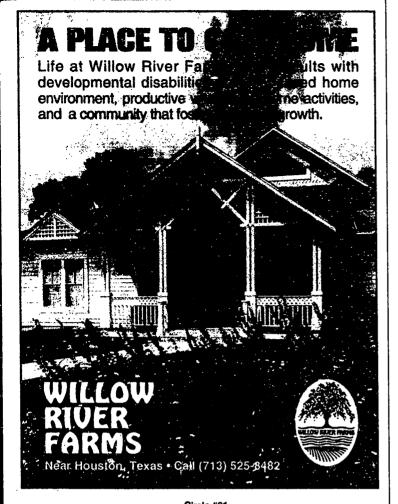
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**EXCEPTIONAL PARENT / NOVEMBER 1995** 

#### NEW PRODUCTS

#### DELUXE, ANGLE-ADJUSTABLE BOWLING RAMP

The Deluxe Angle-Adjustable Bowling Ramp provides the bowler with physical disabilities precise control of the angle of the ball within a 3.5 inch range. Once the ball is placed on the ramp, the rear

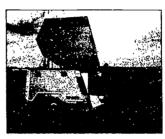


safety stop holds it in position. The bowler aims the ramp and pushes the ball, which rolls down the plastic-coated steel track to the alley. The ramp is 45 inches long, 25 inches wide and 26 inches high.

Maddak, Inc., Pequannock, NJ 07440-1993 Circle # 195

#### TAG ALONG TRAILER

The Tag Along Trailer is designed to transport threeand four-wheeled electric scooters while providing extra space for luggage and folding wheelchairs. The rear



gate, which can be lowered by hand or with an optional electric motor, serves as a ramp, allowing the scooter to be driven directly into the trailer. The top closes and locks for security. The trailer features a fiberglass body with aluminum reinforc-

ing; 8-inch, high-speed highway tires; taillights; brake lights and an interior light.

Tag Along Trailers, Inc., Chippewa Falls, WI 54729 Circle # 196

#### THE BABYSMART BABY WIPES HOLDER

The BabySmart Baby Wipes Holder facilitates hygiene for infants, toddlers and children with incontinence. The unbreakable caddy accommodates square, rectangular or round wipe containers and features a specially designed clip that fastens securely to a changing table,

crib or counter. The caddy grips and holds the container, allowing a caretaker to pull wipes from the counter with one hand.

BabySmart, Watchung, NJ, 07060

Circle # 197



The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on Exceptional Parent's "Free Product & Information Card." Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 995, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

### Marketplace

Information Services Inc.

28 Green Street
Newbury, MA 01951
(800) 659-3399
WriteAway is integrated, DOSbased word-processing and communications software for children
and adults with special needs. It
combines speech output and keyboard scanning with enhanced
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Massachusetts

Atlantic Rehab., inc. 81 Rumford Ave. Waltham, MA 02254-9055

(617) 894-0069
Atlantic Rehab, specializes in Pediatric Mobility and Seating, Sales and Service, Please call for more information.

Missouri

U.S. Medical Corporation 14575 Manchester Road Manchester, MO 63011 (800) 40-USMED/ (800) 408-7633

Consumer Care Products, inc.

P.O. Box 684 Sheboygan, WI 53C82-0684 (414) 459-8353

**Access Medical Supply** 

2006 Crown Plaza Drive Columbus, OH 43235 (800) 242-2460 Attends Youth Briefs fits children 35-75 lbs. \$51.95/cs (96), Free Delivery. Also—Depend, Serenity, other items. Manufacturer's coupons accepted. Free Catalog!

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H.D.I.S.

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5741 Arapahoe Rd., Suite 2A Boulder, CO 80303 (303) 444-CARE (2273) WanderCARE Systems notify caregivers when their wanderer leaves home, Locate them up to ONE MILE away. FREE catalog!

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Full service mobility center, raised
tops/doors, drop floors, custom driving equipment; distributors for
Mobile Tech., Crow River lifts,
Ricon, IMS, EZ Lock, and EMC
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New-Used-Trade-Lease-Buy.
Full sized, mini, rear and side entry.
We carry products from the f
ollowing manufacturers: Braun,
KneeKar, Vantage, Ricon, and PickA-Lift. If we don't have it, we'll find it! Financing is available. NMEDA
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Full service mobility center, raised
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touch pad systems. 41 yrs. of
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214 Valley Street,
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Full-size/Mini-Van
modifications, new/used lifts, drop
floor, raised roof, lockdowns,
driving equip. NMEDA member.
Owned by person with disability.

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Full service mobility center, raised tops/doors, drop floors, custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

# BOOKS, AUDIO/VIDEO & EDUCATIONAL MATERIAL

**Turtle Books** 

Approved by the American Academy of Pediatrics, These upbeat stories with warm, colorful illustrations address real issues found in the lives of real children with disabilities. Provide a bridge of understanding for your children with disabilities, siblings & friends. FREE Brochure.

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Fres—The 1995 Woodbine House/Special-Needs Collection, a catalog of excellent books for parents, children, and professionals on autism, CP, Down syndrome, Tourette syndrome, mental retardation, visual impairment, physical

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Free—The NEW Special Needs Project Book Catalog

The best books from all publishers about disabilities, Comprehensive resources for parents, children & professionals, Special Needs Project, 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.



NOVEMBER 1995 / EXCEPTIONAL PARENT + 83

# CHILDREN'S PAGE

# **Our Differences Make Us Special**

by Aaron Wolfson



Avi is all smiles at the end of his ride down a slide at the school playground.

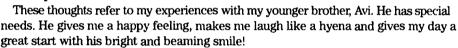
magine a world where everything is the same. It would be pretty boring, right? That's why people who are different should be treated with respect.

People with disabilities are among those people who are different. Some don't talk, walk, read or write as we do. Many of us think that people with disabilities aren't as smart as we are.

Henry David Thoreau said, "If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music he hears, however measured or far away."

This is what Thoreau's words mean to me: if you learn at a certain pace, and your brother learns at a different pace, then let him learn at that pace. Don't force him to learn at your pace. Who says that his level of learning is any worse than yours? He is

distinctly himself.



The school district has given Avi a technical label-"mildly mentally handi-

capped"—which means he can receive certain educational services. This label creates a picture in my mind of Avi riding

down a conveyor belt. A machine slaps a label on his head. The label reads, "This is an Avi and he is handicapped."

But the label does not tell you who Avi really is—that he plays football, collects dinosaurs and gobbles down hot dogs. I know these things about Avi because I've spent lots of time with him and I've gotten to know him.



"Family is very important," writes Aaron's mom, Sara, "and a great source of support." Last year at Passover, the Wolfson children gathered for a group shot: (Clockwise, from left) Avi, 6; cousins Alex, 13, Rebecca, 16, and Michael, 15; Aaron, 10; cousin Havi, 18, and sister Naomi, 8.

People who see Avi for the first time might just go by the label. They could miss out on a nice friendship.

So let's not judge people because they seem different on the outside. On the inside, they are probably the same as you and me. Getting to know people who are different and unique helps you appreciate them. You can make some new friends, and you can learn something. That's why our differences make us special. EP



Two words sum up what it's like to raise Avi-roller coaster! There are manu "downs," such as hospitalizations and loss of skills, and many "ups," like watching Avi perform with classmates in a musical and hearing his hearty laughter. Doug and I have been on this roller coaster ride for seven years. To think we used to joke about hating that particular amusement pari ride-how funny and unpredictable life can be!

A pair of wizards! Aaron

magic together during a

years ago.

and his brother Avi worked

Halloween celebration two

It was Aaron's own decision to make Avi the subject for his speech. We are proud that Aaron has made Avi a big part of his life. Aaron has taught his friends how special young 'r brothers can be.

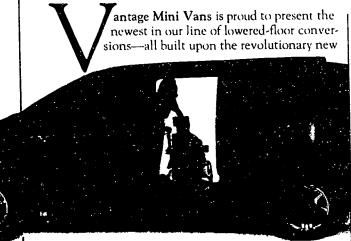
-Sara Wolfson

Aaron Wolfson, a sixth grader at Rockbrook Elementary School, gave this specch last year in a contest entitled, "Celebrate Our Differences." Auron, 11, lives in Omaha, Nebraska, with his parents, Sara and Doug, brother Avi, 6, and sister Naomi, 9. He enjoys reading and sports, and would like to be a computer programmer.

the Children's Page wolcomes contributions from children with disabilities, their siblings and their triends. Be creativel Send your stories, photos and artwork to: Children's Page, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.



# We're Giving Transportation a Whole New Angle!



Chrysler minivans. And, in true Vantage style, we've given them a whole new angle...literally!

#### DOUBLE THE CONVENIENCE

Chrysler is the first manufacturer in the world to offer two sliding side doors—on both the passenger and driver sides—on all of their minivan models. And Vantage Mini Vans, the leader in technological innovation in our industry, is the first to capture its true potential with our available driver-side manual folding ramp. Now you have even greater convenience and flexibility in awkward parking situations.

Unlike most competitors, Vantage offers <u>true</u> <u>lowered-floor access</u> on all of our dual-door models. This means we've extended the driver-side sliding door opening so it is flush with the lowered floor of the vehicle, offering the same low incline for wheelchair and ambulatory access as the passenger side. Whether or not you choose the optional second ramp, this feature alone makes entry and loading of your Chrysler minivan easier. And your options for access that much greater. <u>Isn't this what it's all about?</u>

#### OPTIONS APLENTY

As with all Vantage conversions, your Chrysler lowered-floor minivan is available as either the popular and economical *Trekker*, with its easy-to-use manual fold-out ramp; the *Summit*, with its reliable power folding ramp; or the premier *Northstar* edition, with its sleek, under-the-floor sliding ramp. A myriad of options—power transfer seats, remote control keychain access, power lock downs, hand controls and fold-down rear seat foot rests—are also available to truly customize our vehicles to your family's lifestyle.

No one understands the transportation needs of parents with physically challenged children like Vantage Mini Vans. We think you'll agree...

Vantage is your <u>best angle</u> on lowered-floor minivans.

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#### **RJ Cooper & Associates**

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<u>Really Special Software</u> by RJ Cooper (research, design, production, programming, field testing, distribution) & Bryan Koeff (graphics, animation).

- * We will send you a demo version of any software product in this catalog!
- * We accept purchase orders, VISA/MC, or we can send COD.
- * Unused or un-wanted disks...please return them to us or pass them on.
- * ALL OUR APPLE II SOFTWARE SUPPORT ECHO SPEECH PRODUCTS.
- ⋆ Our Windows software supports any Windows-compatible sound card.
- * For both Mac and Windows, we recommend you get a good pair of amplified speakers at your local consumer electronics store!

#### Pricing info:

Apple II software - \$75
Mac or Windows software - \$89
CrossScanner - \$249
SAM - \$120

Shipping & handling, add 10%.

Prices are quoted in US Currency.

#### Computer types:

Apple=IIc, IIe (128K), IIgs or LC with IIe card, 5.25" floppy.

PC=IBM compatible with Windows. Mac=any color Mac.

We're still busy working on our Apple to **PC & Mac** conversions.

RJ's story: During my 3 years of Electrical Engineering (w/digital emphasis) at the University of Utah, I started working with special students at local schools in and around Salt Lake City. I realized that not many R & D people were working with materials for persons with severe disabilities. I began researching, and eventually developing materials that responded to requests of spec. ed. teachers, speech/language pathologists, and professionals that I began networking with around the world.

I moved to CA in 1986 and finished my B.A. in Developmental Psychology, while continuing my research, this time at RH Dana Exceptional Needs Facility in Dana Point. At the same time, I began writing my column for the internationally recognized publication, Closing The Gap.

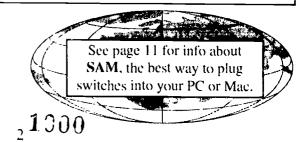
I started, and continue, to make materials that are requested by others, many that know more about needs than myself. I research & develop these materials in actual settings, with actual people, for professionals and parents that have shown a belief in my work.

Trying to respond to your requests and keeping pace with ever-developing technology have

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# TUPH-JALKING



Availability: Mac & Windows - now!

I invented this concept while working with a little lady named Katie from CA. She knows cause/effect, and I wanted her to be able to interact appropriately in a conversation.

Turn-Talking takes the non-verbal person that needs conversation, on a guided tour of taking turns to talk (like turn-taking, only talking!). A supervisor writes a script, and has a person, close in age to the *talker*, record the *talker*'s phrases. Turn-Talking then conducts that conversation.

As with all my newer software, you customize Turn-Talking by writing the scripts, and doing the recording. You can even import your own pictures to represent the Turn-Talkers, or use the provided ones.

# Find The Buttons

I wrote Find the Buttons specifically for Jimmy V of NJ. His mom, Harriet, ealled and we brainstormed this program, and voila, here it is! Basically, this is the only program I know of that teaches a young blind child about graphical user interfaces (GUI). There are 10 buttons you can size and move. As you pass over one, a customized indicator sound is heard. As you leave one, enother sound is heard. Whenever you're in the 'margins', where there is no buttons, then another sound is heard. In this manner, auditory feedback always indicates the movements of the mouse. You then click on the button you want, yielding a more detailed sound.



Availability: Mac & Windows - now!

You can record the button indicators and the button sounds yourself. In fact, it works best that way. I provide some starter screens but you'll have more fun and variety if you do the recording. You can tell a story, have funny sounds; the possibilities are limitless.



### The Switch Progressions



Adult, Teenage, <u>or</u> Children's (choose one)

These disks use cartoon-like simulations about real life to start learners with cause/effect and *move* them to timed, purposeful interactions.

Graphics are age-appropriate. And you have complete control over how the learner interacts, as with *all* of our software!

Availability: Apple II: all of them - now; Mac & Windows: Adult CD - spring, 96

Mac & Windows: Children's & Teenage - now!!

Works with: keyboard, switch, or TouchWindow, or mouseclick

The <u>Switch Progressions</u> are some of the only software (we know of) that help to teach "wait!"

# Spell-A-Word or 2+2

These large-print, early academic programs (available separately) are for beginning to advanced letter and number users. Both disks use an errorless learning Spell-A-Word method. works on identification, spelling, word recognition (for reading). 2+2 works on early arithmetic Both have drill and test problems. modes, which you can set.



These disks are designed for you to **easily** enter lists of spelling words, or arithmetic problems (like 2+2=4), for the learner to practice and be tested on.

Availability: All - now!!

Works with: keyboard, any device capable of producing keystrokes, or switch,



# Early & Advanced Switch Games

Our biggest seller, and our oldest product. This broad variety of switch games is a collection of 19 activities ranging from cause & effect, through following directions, matching, all the way up to using the switch to make a funny face (and print out). And now it's been upgraded for Mac & Windows; it's bigger and better than ever!

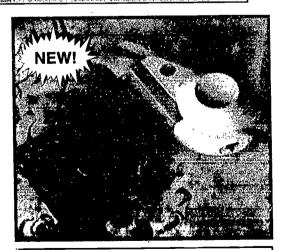


Availability: All - now!!

Works with: keyboard, switch, TouchWindow

# WakerShaker

11 years of work with During my persons that have severe cognitive understanding, I have searched for the ultimate cause/effect device. I created it with the CooperCar, but WakerShaker (the white object on the right) is a close second. It is is far more convenient, not to mention. far less expensive. Do not take WakerShaker lightly. Yes, it's a simple switch modified massager (vibration device), but you simply will not get better. quicker results about what a switch can do. That, after all, is what you're trying to teach with cause/effect training. Besides, WakerShaker is fun! If you are working with a person that needs to understand the power of a switch, you need WakerShaker. I wouldn't say it, unless I felt I really knew!



WakerShaker is \$50.

Add \$20 for a simple switch as pictured,
or use any switch you have.

(Actual WakerShaker may differ slightly from picture)

# 101 Animations



Here's a simple cause and effect activity that simply puts a large and loud animation (non-age-specific cartoon) on the screen with every switch activation. How many animations? 101, of course!

Availability:
Mac and Windows - now
Works with:
switch, TouchWindow



# Faciacia de

wanted the ultimate cause/effect musical music program, totally appropriate for all ages, but really targeted at teenagers. There's plenty of break dancing on the screen and the music is RADICAL. This disk is usable at a slightly higher than cause/ effect level also and comes with a variety of songs. The 3 modes let you target cause/effect or allow the user to be the DJ.



Availability: Ilgs, Mac (20 songs), Windows (10 songs) - now Works with: switch, mouseclick.

Windows requires a sound card. Good, external speakers recommended for all!



# Chasside Anex

CrossScanner is a universal way to run all non-adapted software by single switch, or any pointing device. Using a single switch plugged into any device capable of producing a mouse-click, such as SAM, or any device that can be the mouse, such as a mouse, joystick, trackball, and several others, the user is able to perform mouse moves and clicks, double clicks, drags, operate menu's and enter text. The user interface is incredibly intuitive. All operation is supervisor-controllable to fine tune CrossScanner to the needs of the user.

Availability: Mac and Windows - FIOW

Works with: any device capable of being the mouse-click (single switch mode) or any pointing device (direct select) The line comes down...the

if inger goes across.

Use a single switch to control both.

The first click starts the lineScan down the screen. The next click stops the line when it gets to the user's desired vertical point. If DoubleClick, Drag, or Text Entry is active, an iconWindow pops up for the user to select between with the fingerScan. The final click tells the computer to move the cursor to that point and perform the chosen function.



Finally, BIG cursors for your Macintosh! This control panel allows you to choose from between 4 really large cursors, that work in/with any program. Two of them, actual size, are at the right.





Availability: Mac only - now! Only \$29!



# THE COUPERCIE

### Accept no imitations! Ask for it by name!

Our CooperCar Conversion
Kit adapts this 'kid-car' so that
even the most disabled child
can drive in safety...using
whatever ability he/she has:
wiggle a toe, move a finger,
rotate his/her head...anything!

#### The CooperCar consists of:

1. The BOSS vehicle power base - \$400; with a Premium Charger. We only have a limited number of BOSSes left so you best hurry!



- 2. The CooperCar Conversion Kit, which is the heart of The CooperCar, consists of our computerized electronics, joystick, switch, bungies, & video \$700. Use your own adaptive seat, switches, and mounting, if you have.
- 3. The wireless remote safety override \$150. Useful for safety (obviously), but also great for turn instruction and assistance. Wired over-rides are included with the normal kit.
- 4. The Magic Arm is an incredibly moveable arm which allows you to position the joystick/switch wherever it needs to be, and it stays there \$200.
- 5. Footrests (specify S,M,L) \$125.

Please understand that <u>you take full</u> <u>responsibility</u> for operation and safety of The CooperCar. Because it is a kit, we cannot be held liable for the manner in which you've assembled and are operating the vehicle.

The CooperCar is very easy to adapt. Just follow the video that comes with your Conversion Kit. Basically you're just plugging in 6 wires; no soldering; no cutting!

The CooperCar has Speed,
Acceleration, and Time controls (Time is for those that can't maintain contact with their controller, the CooperCar will travel in the chosen direction for a certain Time). There are switch inputs for the 4 directions, and a proportional joystick input. The joystick can also be put into Pull=Forward mode.





#### Combine Technology and Family Fun...

...during a week of exploration and learning!

Haven't you wished, time and again, that you could spend time watching, learning, and interacting with someone like RJ Cooper while he works, personally, with your special needs family member? Hundreds of you have seen RJ in action, or spoken with him, and expressed this exact desire.

Many parents and professionals feel that RJ may be the best in the world for stimulating and motivating persons with severe to profound disabilities, either physical and/or cognitive.



Also, through interacting with hundreds of family members, RJ is uniquely qualified to implement just about any adaptive technology with the special needs family member and teach other family members about that technology and the adaptations necessary!

Sessions take place in the morning so the afternoons are free for such popular attractions as Disneyland, Sea World, Knott's Berry Farm, Los Angeles, San Diego, whale watching (in season), ocean fishing, beach-going, and a variety of other activities, all within 1 hour. There are even options for taking the other kids on excursions while the parents and special needs family member are intensely exploring technology options, hands-on! Or, RJ will structure the sessions so that <u>all</u> family members participate in the technology fun.

Each month, <u>year-round</u>. RJ will give 2 families the opportunity to come to sunny southern California, with their entire families (yes, your able-bodied kids also!). You will work with RJ, personally, for 2 hours each day for 4 days. The first hour will be with your family members that need to know more about technology, learning exactly how to operate the specific software and hardware necessary to cultivate growth in your special needs family member (even The CooperCar, when appropriate!). The second hour will focus on interaction, between RJ and your special needs family member, you, and any other family members you wish to be involved. RJ will try different software and hardware ideas, attempting to stimulate significant changes in their behavior, learning, communication, and understanding.

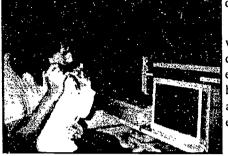
You will leave RJ's Tech Week with a new motivation and knowledge of the software, hardware, methods, and materials necessary to really get things going back home.

Several lodging packages are available, but space is very limited so...

Call or write for a specific brochure on RJ's Tech Week!



I have lectured at over 500 facilities, on 3 continents. My expertise ranges from severe/profound to mild MR or LD. Most of my experience is with children, but many recognize my research & developments with adults also.



Lectures/workshops take a hot-seat, hands-on approach, where members of the audience are called upon to demonstrate on-stage equipment during the workshop. For each period of lecture, I request an equal time working hands-on with individual learners and staff, demonstrating and exploring methods and materials, and adding to everyone's knowledge base, including my own.

I'd like to really connect with you and your learners!

#### Topics include:

Adaptive Mobility for Young Children: Secrets of The CooperCar

Making the Most of RJ's Software

Early Communication Skills and

Augmentative Communication Training

Making Your Most Challenging Learners Successful

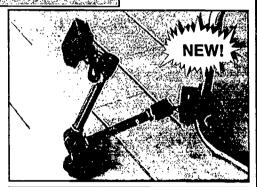
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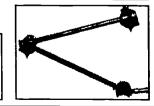
# The Magic Arm System

This arm has changed the way I work with switches. Pictured here with one of our simple switches, the Magic Arm attaches securely to just about anything: wheelchair tubing, tables, the CooperCar rollbar, you name it! The dial at the *elbow* tightens all three joints: the one at the base, the elbow, and the switch end. And when it's tight, it REALLY holds everything in perfect place. This arm is **infinitely** adjustable, and **stays** where you put it. Talk about perfect positioning...YES! You can attach any switch, joystick, or SAM to its end-plate.



\$200 as pictured above

I realize the cost of the 'real' Magic Arm may be prohibitive, so I am also making available its little brother, the Articulated Arm. It, also, is infinitely flexible, but has three knobs to tighten, versus one, and is not quite as strong as the Magic Arm. \$100 with Super Clamp.





## Switch-Adapted Mouse

Now you can plug your switch(es) into our Switch-Adapted Mouse (<u>SAM</u>) device for your PC or Mac for a *variety* of purposes!

- 1) Operate all special needs software that can be operated by a mouseclick (like ours!) or simple keystroke(s).
- 2) Access all regular software, like that from any computer store! The switch-user does all the clicking of the mouse, through SAM, while you move it. This turns any computer activity into great cooperative fun.
- 3) Allow a person with gross-motor hand (or fine-motor head) control to move the mouse, and do the clicking.



You simply plug SAM where your current mouse is, and plug your switch(es) into SAM. A switch plugged into one of SAM's 3 switch inputs acts as the corresponding button, function (click, double click), or defined keystroke[s]. The middle button is a useful drag-lock.



I also make SAM as a joystick. It also has a click, double click, and drag switch inputs. I've seen this joystick really change lives! When you push the stick, the cursor does **not** go flying, no matter what the user does. It simply moves in that direction at a given speed, controllable by the supervisor from a switch underneath. I recommend mounting SAM to a CooperCar arm, for optimal positioning.

PC or Mac - \$120 Add \$20 for a simple switch.

PC users - you <u>MUST</u> specify serial (9 pin) or PS/2 (round) connector for the SAM-TRACKball. SAM-JOYstick plugs into your joystick port, usually found on your sound card.

(Remember, please add 10% for shipping and handling)

## BLULD-A-SCENE



Designed to teach correspondence (between cause and effect), this disk uses colorful large. graphics. auditory feedback, and plenty quality digitized high speech. Each activation adds another part of a scene to the picture. You can take a trip to the Beach, Breakfast table, Park, or Zoo.

Availability: Apple II-now; Mac & Windows - winter, 95/96.

Works with: keyboard, switch, Touchwindow

## The Human Being Machine

A recreational disk that you can also use to teach about the body. The learner scans and chooses body parts, from a fun selection, to assemble a human being of their choosing. You can then print out the body or face in several ways.



Peggy Morrison, a speech/language pathologist friend of ours originally authored **BodyBuilder**. We combined this with **Looney Goonies**, a face building program, that Bryan (see top of page 2) wrote years ago. RJ then put his special touches on them while adding high quality speech, talking menus, etc.

Availability: Apple - now; Mac & Windows - winter, 95/96.

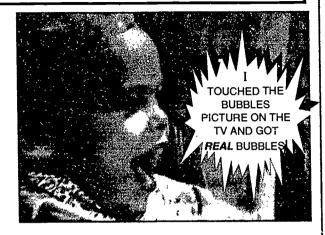
Works with: keyboard, switch, TouchWindow.



## **Point To Pictures** (PTP for TouchWindow or pointing devices)

Picture Scanner (PS for switches), and the R.I ClipArt Disks

To learn about, and use pictures for communication, these are some of the only materials available that focus on real, available, things. Using the communication or 'You Find' modes, you choose groups of pictures with which the learner will interact, from the:

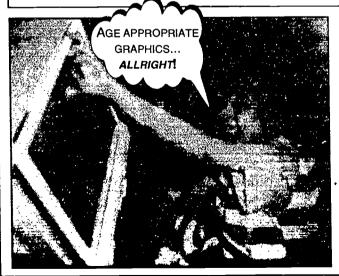


RJ ClipArt Disks (these each require either PTP or PS): Letters, Numbers, Shapes, Toys & Adult Appliances, Mayer-Johnson (MJ) Picture Communication Symbols (PCS), Things (misc. immediate reinforceables)

* To present early academics at the most basic level, use PTP or PS with the Letters, Numbers, or Shapes RJ ClipArt Disks. You choose, from a great variety, which concepts the learner practices.

Availability: Apple II - all disks now available; Mac & Windows - winter '95-96

Works with: PTP can use the TouchWindow (on the monitor or horizontally, on a surface),
Power Pad, or any other touchpad that can produce the numbers 1-9 (like a Concept,
Intellikeys, or Unicorn alternative keyboard). PS uses 1 or 2 switches.

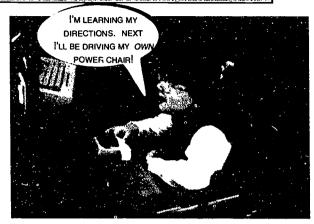


Remember, with PTP and PS you can author specific lessons for your learner, choosing only those pictures that are personally motivating him/her. for included from the optional RJ ClipArt disks. Each item on a ClipArt disk has high quality digitized and colorful speech. animations designed to functional and fun!



## SOKSTICK WIRKINGS

Practicing joystick skills by computer is a lot safer than experimenting with a power chair! This disk starts at a very early motor and cognitive level, and progresses thru 9 activities of increasing challenge. We know of no other program that trains joystick skills like this one.



Availability: Apple-now; Mac and Windows - summer, 95 Works with: SAM-Joystick (see page 11)

If you look at page 11, you will see my new SAM joystick, which controls the cursor (arrow) just like a mouse! With this great device, you are able to operate all <u>regular</u> software. There are many simple regular titles that really lend themselves to early, intermediate, and advanced joystick control. You may use any of these commercial products with SAM-Joystick. Please call for more details. I'd love to discuss this with you and get your feedback.

Internet: Point your browser to <a href="http://www.rjcooper.com">http://www.rjcooper.com</a> and visit our pages on the World Wide Web! Be sure to download RJ's Movie Viewer so you can view the programs available there. It's almost like being in an arcade. I'll be working on some pseudo-Virtual Reality navigation through my pages, so I hope I see you there!



The way that I prioritize my developments is by feedback from you. If you want a project completed faster, don't be afraid to bug me (call or write). When I know a product is really needed, I work harder and I prioritize that project. So take advantage of this direct link to a developer and stay in touch!



## RJ's Demo Order Form

Please check computer type: Windows Mac Apple II type (includes LC w/IIe card)	Please verify your name/address on	
Find The Buttons Turn-Talking 101 Animations RadSounds CrossScanner Spell-A-Word	the bottom back of this form.	
Early & Advanced Switch Games 2+2 Switch Progressions: Children's Teenage Adult		
Build-A-Scene Joystick Trainer The Human Being M	lachine	
Point To Pictures (PTP) Picture Scanner (PS)		
RJ ClipArt Disks: (These each require PTP or PS; see page 13)		
Mayer-Johnson PCS Things Toys & Adult Appliances		
Letters Numbers Shapes		
Please note: if the disk you requested is not ready yet, on the com requested, we will send it upon completion.	puter type you've	

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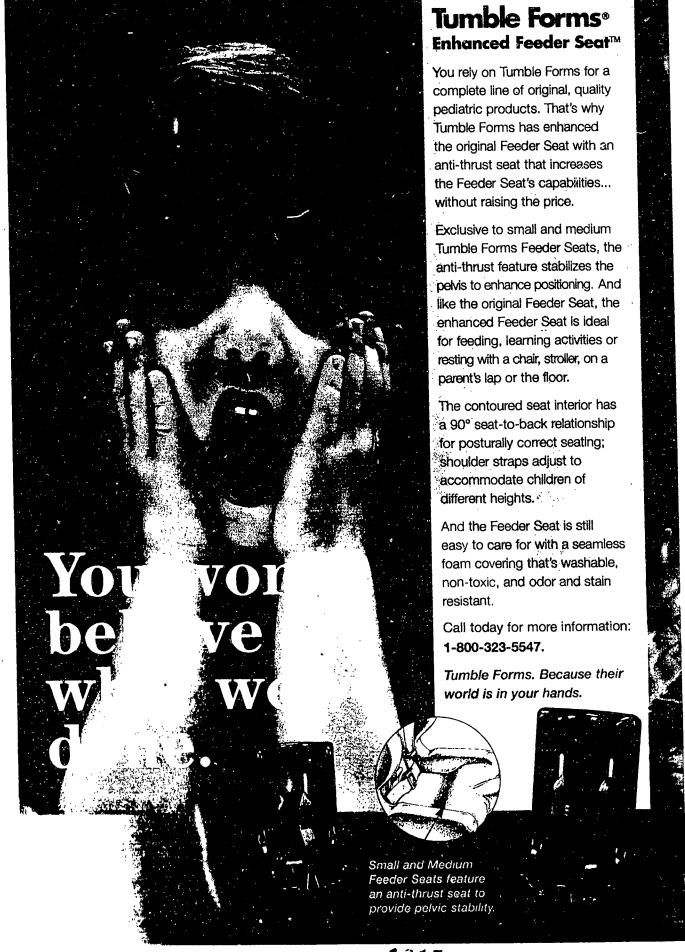
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## **MOVE International**

GIVING CHILDREN INDEPENDENT MOBILITY AND CHOICES

## MARKUS SMITH Working toward a dream

arkus' physical therapist, Darron Veh, called me in October of 1994. He wanted to "try something different" with my son. Markus is 10 years old and has cerebral palsy. We had "tried" many different

things to improve his motor abilities, but Markus had made little progress in the last several years. Markus could stand in a prone stander, but hated it. He could wheel himself slowly and erratically in his wheelchair, but required assistance to travel any distance. His poor vision made motorized mobility risky. What type of experiment were we going to subject Markus to this time?

Darron introduced us to MOVE and the Gait Trainer and Mobile Stander, Markus loved the

stander and was immediately able to wheel himself around in an upright position. Markus then tried the Gait Trainer. He struggled, but couldn't quite get it moving. As a team, we discussed which piece of equipment Markus should work with. We decided to work with the Gait Trainer because it would provide more room for improvement.

Markus initially required every prompt on the Galt Trainer and assistance to make it move. These struggles in the school hallways produced benefits far beyond the physical. Markus' schoolmates stopped to encourage him. A class of eighth graders gave him a spontaneous ovation. Teachers and students encouraged Markus and applauded his every



little success. His self confidence began to grow.

A year ago, Markus told a doctor, "My greatest hope is to walk someday." He was now taking his first steps toward this dream.

After just four months, Markus is able to walk 30 to 40 minutes a day in his Gait Trainer, for distances of up to a half a mile. He now requires only the forearm supports and one leg prompt. He still has trouble controlling his direction, but the power is all his.

Markus has moved out of a wheelchair desk, and into a "regular" desk. He said, "I love having a desk like the other kids. I can get my own books and pencils and that other stuff." Even Markus' wheeled mobility has improved. His wheelchair speed has tripled, and he now wheels himself around the school completely independently.

My husband, Michael, has always felt Markus could walk if we could find the right equipment to give him the support he needed. We finally found

the equipment and the approach. We look forward, with anticipation, to seeing what Markus can accomplish next.

-Gilda Smith, with Darron D. Veh

Markus Smith is a third grade student at Nickerson Elementary School in Nickerson, Kansas.

Darron D. Veh, P. T., is a physical therapist with Reno County Education Cooperative, which provides special education services to Nickerson Elementary School students.



For more information, contact:

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# **PARENTING**

The Magazine for Families and Professionals -

# DECEMBER 1995 VOL. 25. ISSUE 12

Your CHILD OR YOUNG ADULT WITH A DISABILITY

Since1971



PAGE 68

## **FAMILY**

Grandparents Have Special Needs, Too by Jane Johnson	
"Normal"—A Grandmother's Point of View by Diane Bennett" "Mackenzie came into my life and changed everything."	32
Readers Talk About: Family	34
THE IMPORTANCE OF FAMILY by Kathy Carew	
LOVE + INCLUSION = FAMILY by June Hettel	
PAPA AND NONIE by Susan Moore	
GRAMMY'S FAVORITE by Cheryl Paquette	
Best Friends by Lisa Voisin	
"Project Cousins" by Ann Darby	39
Discovering the joys of family.	



PAGE 29

## **Features**

Estate Planning: Getting Started by Frank L. Brunetti......41

The Reauthorization of the IDEA by Senator	Bill Frist46				
Questions and Answers About Managed Car	re by Family Voices47				
. Departments					
Editor's Desk2					
Letters4	Insurance Covers Only One Wheelchair54				
Search & Respond14	Informational Forum: NETWORKING55				

Role Models: ALVIN LAW......26

Familiar Faces......29

A COMPLETE GUIDE FOR CAREGIVING ......44

Fathers' Voices: Surviving by James Elliott .....49 Ask the Doctor: Atlantoaxial Instability........52

Media: CEREBRAL PALSY:

Cover: "Not a creature was stirring..." Each year, "Papa" Norman Janson reads his four grandchildren a story on Christmas Eve; it helps them pass the time between eating dinner and opening their gifts! Surrounding Papa are (from left) Ellen Moore, 4, Tommy Moore, 11, "Nonie" Jackie Janson, Stephen Moore, 2, and Jimmy Moore, 13. Tommy, who has moderate mental retardation, loves spending time with Papa and Nonie-as does the whole family. Read about the special bond between Tommy and his grandparents in Susan Moore's Readers Talk article, "Papa and Nonie."

Tommy, Ellen, Stephen and Jimmy live with their parents, Susan and James, in Black Jack, Missouri. Papa and Nonie live about a half hour away in Normandy, Missouri. Photo: Dean Benge/Shutter-Bug Photos.



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Directory of Advertisers.....58

What's Happening......62

Exceptional Parent Library......66

by Christopher Brown......68

Children's Page: A REALLY NEAT BROTHER

## EDITOR'S DESK

## **Happy Holidays!**

As we come to the end of a busy and exciting year, all of us at EXCEPTIONAL PARENT would like to extend our best holiday wishes to all our readers. This issue is filled with moving letters and stories from our most reliable resources for editorial wis-



STANLEY D. KLEIN, PH.D.

dom—parents. While more and more professionals are becoming regular readers of the magazine, it is the energy, dedication and feedback of parents that has always sustained us.

#### **Families**

Readers Talk continues to be a wonderful resource, in which many readers have participated. In this issue, as in so many others, the Readers Talk stories and other reader articles inspire us—their creative efforts energize other readers—parents, professionals and people with disabilities.

Readers' stories and letters often relate feelings of being "cheated" and angry when faced with the unexpected responsibilities of parenting a child with disabilities or special health care needs. Later, parents may feel guilty about these initial reactions. Perhaps that guilt will diminish with the knowledge that such difficult feelings and thoughts are normal, healthy, mature and human reactions for parents, grandparents, siblings and other family members. Although reading some of these letters and stories can raise troubling feelings—no matter how much "experience" any reader may have—sharing these feelings can be empowering. Together we can validate the challenges and joys we regularly confront; we can cheer each other on throughout every year.

The love of a family is a unique "natural" resource, growing even as it is shared. People concerned about modern-day "family values" would do well to read about the heroes of this issue—grandparents, cousins and other members of "extended" families. Although families may be separated by emotional or geographic distance, family members can find ways to provide love and support to children with disabilities and their parents.

We were especially pleased to discover support groups for grandparents at PACER, a Parent Training and Information center in Minneapolis, Minnesota. In reaching out to grandparents, PACER breaks new ground and provides a model for other communities. We are interested in learning about other programs for grandparents and great-grandparents, including those who are geographically separated from their families.

#### **Words and Worries from Washington**

It is hard to know what Congress will do next regarding issues such as the funding of Medicaid or the reauthorization of the Individuals with Disabilities Education Act (IDEA). We are therefore pleased to share Senator Bill Frist's (R-TN) remarks on the progress of the reauthorization.

During the second half of this year, we have presented several articles from key Adminstration and Congressional leaders. We will continue our efforts in 1996, confident that before Election Day next November, we will be able to publish what the major Presidential candidates have to say about topics that are relevant to people with disabilities and their families—just as we have done each election year since 1972.

#### **Estate Planning**

At a time of year when we take stock of our lives and cautiously look to the future, we are initiating a new regular department on estate planning. We are eager for questions from readers that can be addressed through this new department.

#### **Our Silver Anniversary**

In 1996, Exceptional Parent will be 25 years old! While it is unlikely we will find a way to mail each reader a piece of birthday cake, each issue during the year will celebrate this milestone—beginning in January with our Annual Resource Guide, the most comprehensive in our history. We are immersed in gathering information for the Guide and malding sure it is presented accurately. We have already contacted hundreds of groups and want to thank everyone involved for their helpful participation.



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## LETTERS

#### The Friendly Skies

Congratulations on your publication of the article entitled "The Friendly Skies" (August 1995). The public needs to learn about the host of available charitable, long-distance air medical transport options.

Unfortunately, the sidebar listed only some of the nearly 30 volunteer pilot organizations providing this type of service. And because the article focused only on those organizations providing services to medically stable individuals, readers might not realize there are at least three charitable air ambulance organizations that provide in-flight medical support.

Actually, there is no practical way you could mention all organizations—nor in any way keep up with where they will fly and under what circumstances. That is why the Air Care Alliance, an umbrella organization committed to assisting and publicizing all known charitable air medical organizations, maintains a 24-hour, toll-free hotline (800/296-1217). One call to this number can provide referrals to

all known, appropriate forms of medical air transport.

Thanks again for running this story. One of our greatest challenges is getting the word out to those who need these services.

Edward R. Boyer Executive Vice President Air Care Alliance Manassas, Virginia

#### **Respecting Choices**

I was alarmed and dismayed by the article "Common Questions About Inclusion" (September 1995). Authors Dorothy Kerzner Lipsky and Alan Gartner claim strong, positive support for inclusion from a few favorable research studies, but, in my opinion, the authors raise many more questions than they answer. How can any study make a generalization about what is appropriate for all children when disabilities vary so widely? Are these studies even relevant? Do we parents need studies to tell us whether inclusion works or doesn't work for our children?

Some of us have children who are medically fragile. Others have children whose nervous systems cannot handle noisy environments or whose academic progress requires specialized instruction. Special education was created to meet special needs such as these. Let's not throw out the baby with the bath water. Of course, full inclusion may be the best option for some children, but parents must unite against it becoming the only option left for any child.

Last year, a teacher in our school district taught a workshop entitled "Making Inclusion Work for All Children." I'm sure this woman had no idea that what her workshop proposed was a violation of the Individuals with Disabilities Education Act (IDEA), which guarantees that a full continuum of placement options be available so each child can be provided with an Individual Education Plan (IEP) based on his or her special needs. Unfortunately, full inclusion seems to be a political movement driven by people who mistakenly see it as an issue of

continued on page 6

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▶ To reach out to parents of children and young adults with disabilities and special

health care needs and to the professionals who serve families

To empower parents and professionals by providing practical information and emotional support.

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## 1023



## LETTERS

continued from page 4

civil rights, rather than education.

Don't get me wrong; I support full inclusion for any child with disabilities who can learn in a regular education classroom with appropriate supports. I wish with all my heart my child was one of those children!

My son, Andrew, who has pervasive developmental disorder (PDD), is an "included person" in our community, in our family and at his school, where I have struggled to obtain a special program for him in a school district with a "one-size-fits-all" approach to education.

Andrew now spends 70 percent of his time in a self-contained classroom and the rest of the time with a regular first grade class. Full inclusion is the most restrictive environment for my son. Often, in his regular classroom, Andrew becomes extremely anxious when he cannot understand the material being presented. When overwhelmed, he "tunes out" by talking loudly to himself, flapping his hands or reaching out aggressively at other children. "Escape behaviors," as they are commonly called by teachers, mean exactly that—"get me out of here!"

In contrast, Andrew happily joins "circle time" in his self-contained classroom. He enthusiastically participates in a calendar activity, sings songs he knows and works on identifying his full name written on a card. We know that our child's integration into a regular classroom must be very gradual and based on his abilities, not on administrators' desires to cut costs. Some children may have the potential to move out of a special education setting only if we address their special needs early and aggressively.

Inclusion does not have to be an either-or situation. Many schools are trying progressive approaches such as team-teaching, which combines special education and regular education classes, or reverse mainstreaming, in which regular education students integrate special classrooms. These and other creative approaches can make special education students an integral part of regular school life without forcing full inclusion on everyone.

Authors Gartner and Lipsky report that a 1995 study of inclusive education programs done by their center, the National Center on Education Restructuring and Inclusion (NCERI) at The City University of New York, demonstrates that "...school districts across the country are successfully educating students with all types of disabilities-at all levels of severityin inclusive classrooms."

I would ask these authors to think about the audience for whom they are writing: We are the parents in the trenches fighting battles with insensitive systems. We are fully capable of assessing our children's programs. We don't need a study to tell us that inclusion is working so we can go back to sleep and put our trust in school boards and administrators.

Authors Gartner and Lipsky write that parents should make decisions about inclusion based on "...the law, an understanding of relevant research and the family's values."

I would reply by saying that this is not a "family values" issue. Or maybe it is. In our family we value respect for life and respect for the individual needs and differences of every human being. I want for my son what all parents want for their children-that he reaches his full potential, whatever that potential may be.

J.U., California

■I just want to commend **EXCEPTIONAL PARENT for impartially** presenting both sides of such complicated and emotionally-charged issues as inclusion and residential care. You understand that no single answer is right for every child and family.

Take inclusion, for example—inclusion is great in theory, but in real life, it is not always the best alternative. You can't say "all kids with disabilities" any more than you can say "all people with epilepsy," "all women" or "all whites." We are all individuals and should be treated as such.

I applaud the decision of Jill Chester-Haney of Ontario, California ("A Lesson from the 'Inclusion People," September 1995) to place

her child in the school she believes best meets his needs. Jill knows what is best for her child, and no one should challenge her wisdom. Inclusion should always be available, but it is not always right.

D.E., California

■ We had submitted a Readers Talk piece for the September issue entitled "The Politics of Inclusion: One Family's Journey." Although we were disappointed that our story was not published, we were very pleased with that issue's coverage of topics related to education. The articles were excellent and the Readers Talk pieces provided a balanced view of inclusion.

We are currently fighting the New York City Board of Education to get inclusion for our son, so we really appreciate your coverage of this topic. We are sure that the September issue of the magazine has helped parents become more knowledgeable. I know it has given those of us "in the heat of the battle" the strength to pursue our vision, knowing that we are not alone in the struggle.

L.L. & S.K., New York

#### "Genetic Counseling" Clarification

I was pleased to be interviewed for "Genetic Counseling: Part Two" (September 1995). The article concerns a subject about which it is increasingly important to be wellinformed, as the boundaries of genetic knowledge expand rapidly. However, I would like to clarify and correct my comments as quoted.

I was disappointed that the article omitted the essential fact that I am the proud parent of a seven-year-old daughter with Down syndrome. Having a child with Down syndrome has led me to reflect on the meaning and value of her life and the lives of others who can be said to have some sort of genetic "defect." My parenting experiences have made a significant difference in my perspective on these issues. My professional experiences with other parents and chil-

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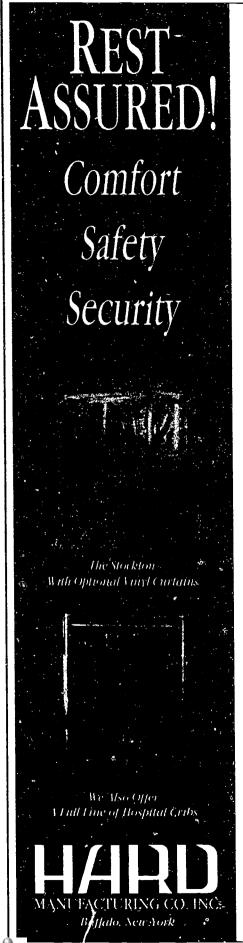
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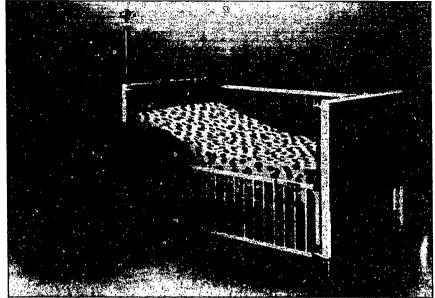








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continued from page 7

dren also inform my views on the importance of complete and accurate information in genetic counseling.

I am concerned that my statements, as printed, appear unduly critical of those engaged in genetic counseling. Although I believe that expectant parents frequently receive excessively negative and incomplete information, I did not intend to imply that those in the field are uniformly or deliberately negligent. My statement about the information people are given regarding the risk of and prognosis for heart defects in children with Down syndrome appears slanted because the word "often" appears in the wrong sentence. In fact, I said, "People are told that 30 to 40 percent of children with Down syndrome will have a heart defect, which is accurate. But they often are not told that, now, most of these heart problems are correctable."

I was trying to make the point that what is unsaid can be as important as

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what is said. While it should be assumed that any professional who provides genetic counseling is wellversed in the scientific facts concerning risk, diagnosis and prognosis, parents have the right to hear more, especially that which is encouraging and affirming. Much of what is most significant to parents—the "prognosis" for their child's future life-cannot be reduced to numbers and facts. Those of us who live with and love children with disabilities have learned that many things that would once have seemed unthinkable or unbearable-a diagnosis, a procedure or an obstaclecan indeed be borne or overcome for the sake of our children. This knowledge comes most surely through personal experience.

Clinicians may need to be more deliberate in their efforts to stay upto-date not only with medical advances (for example, the availability of successful open heart surgery for

previously inoperable defects), but also with the ways in which children and families are living with genetic conditions. Advances in medical care and educational, social and vocational opportunities are constantly changing the expectations and possibilities for babies born with Down syndrome or a host of other conditions. In addition, current research indicates that a child with a disability does not inevitably have a negative impact on family functioning; that old belief is mistaken.

Since genetic counselors may not have the opportunity to experience the joy that accompanies a long-awaited first word or the daily good-night kiss of a child with Down syndrome. I believe it is beneficial for them to work closely with parent groups or other resources that can provide this vital perspective to prospective parents faced with a most challenging decision. As genetic research increases the number of conditions that may continued on page 12

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be identified before birth, there is also an increased need for such collaboration, along with open, inform the communication. No one can offer the contract on a child's future, but a concerted effort can present a sketch of the possibilities and pitfalls, as well as some tools for adding detail and vigor to the picture.

Susan Morse-Fortier, Massachusetts

### Inspired by "Karate Kid"

"The Karate Kid" (Children's Page, October 1995) was a very inspiring article. Barry's karate instructor is a beautiful example of the importance of these exceptional human beings in the lives of our special kids.

We live in Costa Rica, where I spent many months looking for a preschool that would accept and appreciate our two-year-old daughter, who has mild spastic diplegia cerebral palsy. Every place I went gave me a different reason for rejecting her.

Finally I found the director of a small Montessori school who not only wanted our daughter, she sought *us* out! This woman is like a hero to me. Janie is thriving in the Montessori school, and her teacher welcomes communication between us in ways that directly benefit our daughter. In these times when many of our children's gains are being threatened, such exemplary people are especially valuable.

B.M., Heredia, Costa Rica

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**Understanding Enuresis** 

The article "Understanding Enuresis" (August 1995) should have mentioned that diabetes insipidus, albeit rare, can be a cause of enuresis. An under-diagnosed disease, diabetes insipidus has no cure. If not properly managed, the condition is life-threatening, due to either dehydration or water intoxication.

I know this because my seven-yearold son has diabetes insipidus. He is totally deficient in vasopressin (the antidiuretic hormone, or ADH) and arginine, the main amino acid precursor to vasopressin.

I have met many parents whose physicians did not properly diagnose their child or reacted skeptically to a diagnosis made by another physician. The medical community needs to learn more about diabetes insipidus. Diabetes insipidus is not the same thing as insulin-dependent diabetes. And it's not *just* excessive thirst and urination; diabetes insipidus means problems with fatigue, body temperature regulation, behavior, learning and memory. Yes, America, there really is another diabetes!

M.A., Maryland

EDITOR'S NOTE: The Diabetes Insipidus and Related Disorders Network (c/o Beth Perry, 1622 185th St., Creston, IA 50801-8172; 515/782-7838) is an informal network of families and individuals affected by this condition. The network publishes an occasional newsletter and can help parents of children with diabetes insipidus contact one other:

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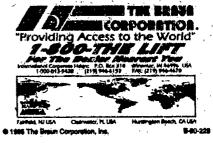
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## SEARCH

### Leg Braces and Ripped Clothing

My six-year-old daughter, Maria, was born with spina bifida. We live in South America, but we bring Maria to Boston every year to see her doctors.

With leg braces (reciprocating gait orthoses, or RGOs) and a walker, Maria is now walking very well. However, her walking has led to a problem: Maria, who is very fashion-conscious, likes to dress up every day to go to school, but she rips and destroys her clothing when the material gets caught between her braces and the walker.

This probably sounds like an insignificant problem, but Maria doesn't have one piece of clothing that is not ripped. I don't know of any other children in Cali, Colombia who use leg braces and walkers. I would really like to hear from other parents who can share their experiences concerning little girls, dresses, leg braces and walkers. I believe it is very important for parents to be in touch with others who have children with the same kind of disability, so we can share both simple and complicated experiences. M.R., Cali, Colombia

**Langer-Giedion Syndrome** 

Our 18-month-old son has been diagnosed with Langer-Giedion syndrome (also known as trichorhinophalangeal syndrome, Type II), a rare chromosomal abnormality. Ben has a tiny interstitial rearrangement affecting two bands on chromosome eight.

Ben is a delightful child-bright, funny and loving. He does not appear to have any mental retardation. He was born with some subtle facial differences, which have since "normalized," according to his doctor. His ears are the only exception; both stick out, and one is smaller and missing a fold. Ben also has low muscle tone and is very small for his age (18 pounds at 18 months). He is currently being tested for a suspected mild hearing loss, and we have just discovered the first piece of "bony growth"-another characteristic of this syndrome—on one of his shoulder blades.

We would love to share information and support with other parents of children with this condition.

L.K., Toronto, Canada

EDITOR'S NOTE: The National Foundation for Ectodermal Dysplasias (P.O. Box 114, Mascoutah, IL 62258-0114; 618/566-2020; 618/566-4718, fax) can provide information about Langer-Giedion syndrome and can put you in touch with other families who have children with this condition. (Both types of trichorhinophalangeal syndrome are forms of ectodermal dysplasia.)

#### Failure to Thrive and Scoliosis

Our youngest daughter, Hannah, is 19 months old. She was born with an extremely rare condition known as Aicardi syndrome, in which the corpus callosum (the band of fibers connecting the two hemispheres of the brain) fails to develop. Only girls are affected by Aicardi syndrome; it is

believed that affected males die in utero. The condition involves seizures, visual problems, low muscle tone and moderate to severe mental retardation. Girls with the syndrome are usually non-verbal and vary few are mobile. Some have spinal defects; Hannah has severe scoliosis.

We are looking for information on two aspects of Hannah's condition. At this point, Hannah weighs just 15 pounds. She becomes sore after sitting for only a short time because of the lack of fat on her bottom. We can't pick her up by grasping her under the arms; it hurts her because she's so thin. She's been classified as "failure to thrive." Doctors tell us her body does not utilize the nourishment it should from her food. She's always been a poor eater and until about six months ago, refused all solid foods. She is on PediaSure, but only takes about 15 ounces a day. We would like to hear from parents who have battled this problem and won. We need solutions, fast.

Our other question has to do with the "Milwaukee brace" she is supposed to wear for at least 12 hours a day. It is supposed to flatten her back and prevent any further problems from the scoliosis. However, it is extremely uncomfortable. While wearing it, Hannah cries constantly and is unable to do anything as simple as rolling over. The whole family becomes upset, and we finally just remove it. The longest she has kept it on is two and a half hours. She is normally such a happy baby that it's hard to see her so miserable. We would welcome any suggestions.

M.J. & D.J., Kentucky

#### Feeding System?

Our son was hurt in an accident three years ago. He can now move his arms and legs, but not in a coordinated way. We are searching for a feeding system that will allow him to feed himself.

He doesn't have enough forward head movement to use a mechanical feeding system, and he doesn't have enough shoulder movement to use a mobile arm support. Can anyone tell us about another type of feeding system or specific modifications they have been able to use?

M.W., Colorado

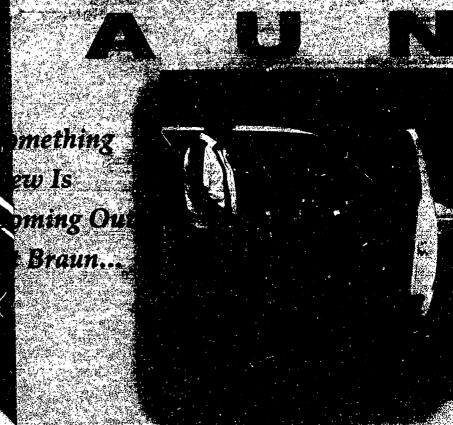
#### Leukoencephilitis

Our "normal" son was diagnosed with T-cell leukemia at the age of five and had a bone marrow transplant (BMT) one year later. Then he was diagnosed with leukoencephilitis, also known as Baló disease, a condition involving a loss of myelin in the brain. This condition apparently occurred as a result of toxicity to chemotherapy during the process of his BMT.

We were told that most children diagnosed with leukoencephilitis die shortly thereafter. My son is now 12 years old and has severe disabilities. He has seizures. He cannot walk or talk, and he has a feeding tube. I would love to talk with other parents of children with leukoencephilitis to find out how those children are doing.

E. L. & F.L., California

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## The Laren Community

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The seat extends 20" and tills forward a full 6" to make bounding side and may. Once on the seat, you are smoothly mised into the relicie by persong the conventently mounted switch. All you have left to do is manually rotate into the forward facing position. To exite the precedure is simply reversed.

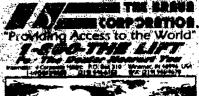
The Companion Seat! utilizes your van's original seat but replaces the existing seat base with a unique power base. When not needed, it handless couldy as the pieces as a This feature makes it paries, for active families with only one member who heads assistance. And, as always, Green theorems assistance. And, as always, Green the required to meet all applicable faderal motor vehicle painty standards.

If you need financial assistance, Chrysler offers cash rebales towards the purchase of adaptive equipment divough the Chrysler Corporation Automobility Program. Ask your local Braim distributor about other sources of assistance.

For more information on the Companion Seate or other Braum mobility products, call us today at 1-800-THE LIFT. We will give you the name and location of distributors in your area.

Now more than ever, mobility is one of the most important things in your life. Let Braun and the Celimpanion Seat be the answer to your needs.

Patents Pending





The Breast Corporation in the historyal front lander for mobility incidents. With four absolute and a morthwide distributor interest, we need to provide the incidents and new front your treed. Over commitment to poor antiquent is also supported by our Three-Year Physic Linested Pharmally, Sample and 1-800-THE LIFT for the Bream dealer material you.

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continued from page 14

#### Caring For an Adult Sibling

My 54-year-old sister, Helen Marie, has mental retardation. She now lives with my mother in Chicago. After my mother dies, she will come to live with my husband and me in Atlanta. Helen Marie is sweet, kind and fairly self-sufficient. She takes pretty good care of herself and, in fact, is a big help to my 78-year-old mother. Helen Marie has worked in a sheltered workshop but would not be able to handle a "regular" job without many accommodations. She can be "stormy" if placed under any pressure, and she does need supervision.

Helen Marie has always lived at home, and I cannot see her adjusting to a more independent life. She knows she will come to live with us in Atianta when my mother dies; in fact, she was part of the decision. She is very comfortable with us, and knows we both love her very much.

Here's the problem: My husband and I both work, and I do not want Helen Marie just hanging out in the house all day, watching TV and being lonely. Nor do I want her "taking care of the house." I want her to have a life, independent of my husband and me. I want her to be able to talk about what she did during the day and what she might do tomorrow. I am afraid if her life becomes a mirror of ours—as much as we love her—she will have lost something. I want her to know she is a separate person with her own thoughts.

My mother hasn't been well, and Helen Marie's world has become smaller since my dad and another sister died. Helen Marie is quieter now, and I feel like she is withdrawing. I don't want her world to become even smaller.

Helen Marie is used to frequent family gatherings and activities in Chicago. I've called different agencies here in Atlanta to see what is available for Helen Marie on a purely social level. None of the agencies can give me any answers while my sister is still in Chicago. As frustrating as that is, I understand. They are dealing with many people who need help now, and I'm looking for ideas for the future.

I hope to hear from someone else who has been in this situation. Can anyone give me hints on making my sister's transition as easy and positive as possible? Helen Marie will already be so sad about losing my mother, and I want so much for her to know that this is her home and we will be there for her—without smothering her separate and worthwhile personality in the process.

K.W., Georgia

#### **Side Effects of Anticonvulsants?**

My four-year-old son, Christopher, was diagnosed with a low grade astrocytoma brain tumor at eight months. He has undergone two surgeries and is on his second round of chemotherapy. He also had a stroke at eight months, which left him with left side weakness.

At 18 months, Christopher was walking and could say 10 words. At that time, he started having seizures. Initially, he was put on Phenobarbital. Then Tegretol was added. His

doctors increased the dosages of both medications in an attempt to get the seizures under control. At that point, he began to stumble when he walked. Within a few months, he was unable to walk, talk or comprehend language. He also started to drool. I suspected that the medications were to blame, but the doctors told me this deterioration was not a side effect of the drugs.

He has been on the same combination of medications for three years now, and his condition has not improved. Has anyone else had similar experiences?

B.D., Colorado

EDITOR'S NOTE: David Hirsch, M.D., Editorial Advisory Board member and ASK THE DOCTOR columnist comments: "If Christopher's astrocytoma is no longer growing or expanding, and if he is not having any side effects from the chemotherapy, and if he has no other structural problems in the brain, such as fluid build-up, it is possible that the medications could be causing some—or in the worst case—all of his problems. Either one of the medications could be responsible, or the problems could be caused by the way this individual child reacts to this particular combination of drugs.

"If Christopher's seizures are stable, have his doctors tried eliminating one medication at a time? If one medication alone could control the seizures, I think it would be better to use only one drug. (There is a higher incidence of side effects with combinations of medications than with sing! "drug treatment.)

"I have seen these types of problems as side effects of anticonvulsants. They certainly are not unusual side effects of these medications, however, most children do not have problems as significant as Christopher's."

Search and Respond is an exportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals

Please indicate whether the letter is a cearch or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax: Search or Respond, Exceptional Parent 209 Harvard St., Ste. 303 Brooldine, MA 02146-5005 Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in Exertinal Passets 1995 Resource Guide (January 1995).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (WTTY) or (706) 632-8630 (Pax).



## New Life Insurance Program

## Easing the financial burden at a time of grief

by Frederic A. Moritz

t's a subject that is sometimes difficult to think about.

Who will take care of the financial burden in a time of grief after the death of a loved one with a disability?

Now there is one new answer.

Protective Life Insurance Company of Birmingham. Alabama has made available a simple, easy-to-apply-for term life insurance policy called Protective Provider. A toll-free call to 1-800-93+-1929 will bring a free information packet on a specially designed term life insurance policy that can be used to cover funeral and burial expenses, or other expenses for children or adults with disabilities.

At a time of grief. Protective Provider can help with the healing. As children grow older, some parents can take comfort in the knowledge that their offspring with disabilities would be cared for in death, without imposing extra financial and emotional burdens on grieving survivors.

"There is a huge need for counseling the families of those with disabilities" says Protective Life's Vice President Mike Ballard. "As we talked to families, we found a need for this product." he explains, "We went to work to see how we could meet this need."

## FINALLY. AFFORDABLE INSURANCE

In the past—given the insurance industry's reluctance to take on clients thought to be at higher risk—it wasn't easy for individuals with disabilities or their caregivers to buy life insurance.

In particular, it may have been difficult to buy more affordable "term life" insurance policies for individuals with disabilities, as

opposed to the more expensive "whole life" policies, which also accumulate cash value.

"There has been some bitterness out there at the difficulty in getting life insurance for those with disabilities," says Rick Larson, who sells insurance for people with disabilities at the Cornerstone Financial Group in Burlington, Massachusetts.

#### THINKING ABOUT INSURANCE

Sometimes there is a reluctance to think about life insurance.

"Unfortunately, a lot of people haven't been prepared... this is one tool in planning for the future," says Dr. Gary Edwards. Executive Director of the United Cerebral Palsy Association of Greater Birmingham.

Dr. Edwards was one of those contacted by Protective Life during the planning phase for its new product, which has been available only for about a month now. In designing the new product. Protective Life planners consulted professionals working with people with disabilities, as well as families themselves, notes Mike Ballard. Vice President at Protective Life.

"It's not a glamorous product or a comfortable issue, but it's a serious issue," says Ballard, "Nobody likes to talk about dying. It's normally a painful and emotional subject... But, unfortunately, people die sooner than they expect."

Individuals who call 1-800-934-1929 will receive an informational folder on Protective Provider, with a clear, non-technical explanation of the policy and benefits, plus a straightforward application form.

"It's a good product," notes United Cerebral continued on page 20



TAKE CARE OF
THE TINANCIAL
BURDEN IN A
TIME OF GRIEF
AFTER THE
DEATH OF A
LOVED ONE WITH
A DISABILITY?



AT A TIME OF GRIEF,
PROTECTIVE PROVIDER
CAN HELP WITH
THE HEALING.



e^{t Pense} needs his

The source of a parent's strength is in the love felt for their child. At Protective Life Insurance Company, the source of our strength is in the resources we have developed since 1907. We understand the importance of caring, planning and meeting needs. That's why we offer the PROTECTIVE PROVIDER⁵⁸, a term life insurance policy developed specifically for people with disabilities. For more information on the PROTECTIVE PROVIDER⁵⁸, call 800-987-6787. At Protective Life, we're someone to lean on at a time when you need it the most.









"NOBODY
LIKES TO
TALK ABOUT
DYING. IT'S
NORMALLY A
PAINFUL AND
EMOTIONAL
SUBJECT..."

c ntinued from page 17

Palsy's Edwards, "I am impressed with Protective's enthusiasm and willingness to do what needs to be done."

Protective Life has been promoting Protective Provider strongly in only a few states, but Ballard says nationwide marketing has now begna.

#### STANDARD PRICE

The Protective Provider provides a standard price for term life insurance in the amounts of \$5,000: \$7,500 or \$10,000, regardless of the disability. Protective Provider's term life insurance can be issued between the ages of five and 55, and is available to age 70. Rates increase, depending on age attained, in five-year blocks. Premium payments may be made annually or semi-annually.

For example, in the age bracket five to 20, the annual premium would be \$110 for a \$5,000 policy; \$130.50 for a \$7,500 policy; and \$140 for a \$10,000 policy. At the age bracket 36 to 40, the annual premium would be \$152 for a \$5,000 policy; \$101.25 for a \$7,500 policy; and \$171 for a \$10,000 policy. In the age bracket 51 to 55, the annual premium would be \$255 for a \$5,000 policy; \$344,25 for a \$7,500 policy; and \$425 for a \$10,000 policy.

The policy does not require a medical examination, although the applicant must answer three medical questions attesting that the individual with a disability 1) is able to move about and eat, even if some assistance is required: 2) is able to function without the use of any artificial life support (e.g., ventilator, feeding tube, etc.); and 3) is free of heart disease, stroke. AIDS and all forms of internal cancer as diagnosed by a physician within the past five years. In the first two years of the policy, death benefits are limited to the return of premium plus interest (in most states). There is a twoyear suicide and contestable period, and benefits are adjusted for misstatement of age. Without these limitations. Protective Life would have had to set the rates much higher.

## A PRECEDENT FROM THE ARC

Protective Provider builds on the precedent for

disability insurance set by The Arc, which offers its members the option to buy life insurance in the amounts of \$2,500; \$5,000 and \$10,000. The Arc's decade-old program is geared mainly to those with mental retardation, explains Rick Fritsche, an Arc organization specialist in Arlington. Texas, "We were able to demonstrate to the underwriters that people with mental retardation are no more medically fragile than individuals without disabilities," he says.

By contrast, Protective Provider is targeted for a wider range of persons with disabilities. Customers who qualify pay the same price regardless of disability and regardless of differing mortality rates.

## PART OF A WIDER PLANNING PROCESS

The Protective Provider death benefit policy is just one of a host of services provided by Protective Life. Protective Provider is available alone or as part of a family's larger planning process.

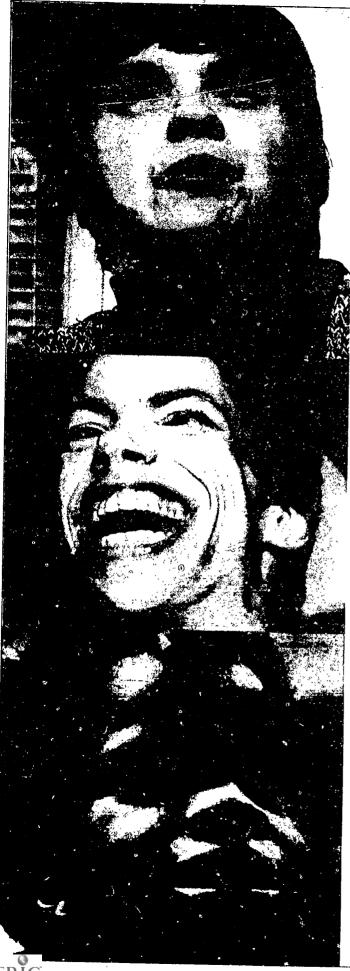
Estate Planning for Persons with Disabilities (EPPD), a Birmingham-based division of Protective Life, is available to work with caregivers and family members with disabilities to develop a comprehensive planning approach to provide for individuals with disabilities when caregivers can no longer function in that role.

In stage one, caregivers write a "letter of intent," summarizing the lifestyle and special needs of family members with disabilities, In stage two, a financial analysis is performed, geared toward determining what would be required to maintain that lifestyle in the event of caregivers' deaths. In stage three, legal requirements, such as a possible need for trusts, are analyzed. An attorney selected by the family can handle such needs. Stage four analyzes possible insurance needs that will permit a surviving family member with a disability to maintain his or her intended lifestyle.

Frederic A. Moritz was a journalist with the CHRISTIN SCHNOT MONITOR for 13 years. He has also taught at Pennsylvania State University and Bucknell University: He is currently a graduate student at Boston College Graduate School of Social Work.



THE PROTECTIVE PROVIDER DEATH BENEFIT POLICY IS JUST ONE OF A HOST OF SERVICES PROVIDED BY PROTECTIVE LIFE 37



# LOOK WHO'S SMILING NOW

Students at Oak Hill School are smiling because they...

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For more information about Oak Hill School's community-based education and residential program for children with severe multiple disabilities, contact the Director of Oak Hill School, 120 Holcomb Street, Hartford, CT 06112, Tel: 860/242-2274, Ext. 851.



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Ircle #282 1038

## RESPOND

## Supervising a "Runner"

L.K. (August 1995) has a three-yearold son, Jimmy, who has autism. Jimmy is considered a "runner;" if he is not constantly supervised, he will run away. L.K. has tried using a tracking device, but Jimmy refuses to keep it on. L.K. wanted to know how other parents of "runners" deal with this problem.

I had to write when I saw the letter about your "runner." There must have been other "runners" in history, but other than yours, mine and the "Wild Boy of Avignon," I've never heard of one.

My 10-year-old son, who has autism, has always been an escape artist. I don't know where he thinks he's going—just out! He wears a medallion necklace from Medic Alert that states his name, address and the fact that he is non-verbal and has autism.

We live in Minnesota so winter

escapes aren't too common, but I usually call our hometown police in the spring to remind them that my son is around. When he gets away from home—usually about twice a year—he tends to go into people's houses. I worry because he's getting large enough that someone might mistake him for a burglar.

Otherwise, I have deadbolt locks on all the doors, and I keep the keys hidden. We have a security system that emits a beep when the door opens; that has foiled several escapes. I've removed all the window cranks and put duct tape over the little pins that hold the screens in place because he takes the screens out, opens the window and climbs out. Fortunately, his fine motor skills are not as good as his gross motor abilities, so he can't get duct tape off, untie knots or unhook chains. I also have locks on most of

the interior doors so I can restrict him to certain areas within the house. This makes it easier to monitor him. Needless to say, I have to lock him in his room at night to keep him from escaping while I'm asleep.

He can never be alone outside. We have a fence, but now that he's bigger, it's easy for him to climb. He still has some tactile defensiveness and doesn't like to be in long grass and bushes, so I've planted a lot of bushes and vines along the fence to discourage climbing.

Making sure my other three children don't leave a gate open used to be a problem. No one could be bothered locking a padlock. Now I have a dog chain that clips the gate closed. My son can't get the clip undone and the others can get in and out easily.

Ours is a strange house to the uninitiated. They are welcomed at the front door and invited in; then the door is

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COVERAGE AVAILABILITY VARIES BY STATE

closed and locked, and I run off to hide the key. We proceed on into the family room, as I lock the living room/dining room to make sure no one (guess who!) turns the table over or pushes the chairs down the stairs. Then I lock the kitchen door to make sure the microwave isn't pulled off the shelf and no one tries to wade in the fish tank. There! Now we sit down and visit!

Still, there are some advantages to having a runner. At school he has always had a one-to-one aide—and he always gets the youngest, strongest, fastest one.

Thinking his frequent escapes might be the expression of an unmet, deepseated need for more exercise, I've tried to take him running with me. Guess what? He won't run even a quarter of a mile on a running path—it must all be in the chase!

This is the first year we've been brave enough to take him on vacation. Both times we've rented a large condo so he can have his own room that is secured for the night. I can do a lot with my trusty duct tape and some nylon cord. Then all I have to do is explain to the other kids why he gets the room with the two double beds and the three of them have to sleep in the tiny loft! Them's the breaks, guys!

I think the hardest part of parenting a "runner" is making some time for them to be a regular kid, to be a little bit free. You manage to come up with all kinds of strategies to keep them in and keep them safe. Finding a way to let them out, and let them take some risks is much harder. I don't have all the answers.

The park programs have provided my son with opportunities to try some

things I could never help him with—snow skiing, water skiing, gymnastics, bowling. I'm always looking for activities that will keep him focused and engaged, so he won't be tempted to wander. The aides in these programs have been excellent. I just have to trust that they will be able to keep up with him, and he will come home at the end of the day.

A.H., Minnesota

#### It Isn't Fair!

K.S. and K.S. (September 1995) have a seven-year-old son with Down syndrome and a two-year-old son who has been diagnosed with neuroblastoma (cancer of the neural cells). They feel overwhelmed caring for two children, both of whom have problems, and wanted to hear from families who have dealt with similar situations. "This just seems so unfair to us," they wrote. "Everyday we ask how God could do this to us twice."

Ten years ago, I became pregnant with my first child. After years of infertility, I had come to accept that I would never have children. Nevertheless, I was thrilled to discover I was pregnant. Books were some of the first things I bought for the baby I was expecting. Intelligence was very important to me, and I planned to read to my child from the very beginning.

When the doctor told me my daughter had Down syndrome, I thought, "God, give me anything but mental retardation." I was knocked to my knees. Still, I decided that, no matter what, she would have a happy childhood.

Three years ago, I took her to see a movie. When we got home, my husband of 14 years was gone. He'd just taken all his things—no note, no goodbye. Our marriage was over. Once again, I was knocked to my knees. My daughter had lost her father, whom she loved dearly. Now, I could not even give her a happy childhood.

continued on page 24

## Tell us about...

## ... parenting twins when one or both have disabilities.

Write to: Readers Talk, ENCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.

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RESPOND

continued from page 23

I made some terrible choices during that very difficult time in my life. I would have done anything to stop the pain I was feeling, even briefly. I became involved in an inappropriate relationship and ended up pregnant.

Although I cannot now imagine life without either of my children, I was devastated when I found out I was pregnant again. I did not want this baby. I could not marry the father and felt I could not offer the child a normal life. I was in desperate straits, both financially and emotionally. I was almost knocked to my knees again—but not quite. My legs were getting stronger.

Last May, my son, then 20 months old, was diagnosed with rhab-domyosarcoma, a highly malignant cancerous tumor of the muscle fibers. This time, maybe I swayed.

I am stronger now than I ever have been. At this point, it would take a hurricane to knock me over.
Whenever I am faced with something frightening, I just remind myself about what I have already survived.
Then I square my shoulders and go forward. I never chose to go through this pain, but I've stopped asking "Why me?"

It's not *me*. My daughter is the one with Down syndrome. I cannot begin to imagine her struggles. I do not know what it is like to be just smart enough to know you are not smart enough. I choose to have her included in a regular classroom because she has to learn to live in our world. But I have never struggled like she does.

My son is the one with cancer. He gets the chemo. He goes through the surgery, the discomfort, the pain and the sickness. He is the one with the life-threatening disease, not me.

Life is not guaranteed to include only a limited number of hardships. I've never believed I was a "special" person to whom God gave "special" children. There are no easy answers. The Bible says God knows when a sparrow falls, not that He keeps the sparrow from falling.

I wish you the best of luck with your struggles. May both of your children have long and fulfilling lives.

V.S., Arizona

■ My husband and I have shared your feelings of "unfairness." We were most comforted by knowing that we were not singled out for rotten treatment. I sense that you need the same reassurance. Here, in a nutshell, is our story:

We have three daughters, now aged seven, four and two. Our first daughter, Elizabeth, was, and still is, an absolute delight—bright, funny, and beautiful. We so marveled at her that we couldn't wait to experience parenthood again.

Our second daughter, Kate, seemed perfectly healthy at birth. However, it soon became apparent that she wasn't developing as she should. When she was 11 months old, she was diagnosed as profoundly deaf. Just when we had gotten over that shock, we learned she had diffuse brain damage, probably as a result of contracting cytomegalovirus (CMV) in utero.

When Kate was two, our third daughter, Alexandra, was born. We had high hopes that Alex would be healthy, because Kate's problem was not genetic. I have to admit that I also felt somewhat "cheated" with Kate—a selfish feeling that has caused a great deal of guilt—and I looked forward to experiencing motherhood with Alex the way I did with Elizabeth.

Alex was born healthy. But at the age of nine weeks, she was diagnosed with neuroblastoma. A tumor on a nerve in her neck was removed, and she began undergoing chemotherapy. After our initial feelings of panic, my husband and I were struck by feelings of unfairness. We had always had faith in God, attended church weekly and treated people as well as we could. So why was this nightmare happening to us?

During my eight-day stay in the hospital with Alex, I embarked on a journey to find the answer to this question. I read the Bible and books written by people who had lived with tragedy. I talked with clergymen, family and friends. And I prayed. Looking back, I realize that this time was a catharsis for me, as well as the deepest religious experience of my life. One night in the hospital, as I held my baby, I had an overwhelming sense that *someone* was caring for my child. I'm not talking miracles or signs, just a sense that God loved my child.

I came to the conclusion that God didn't "do this" to Alex, that He was as sad about her sickness as we were. Somehow, to believe He was on our side helped me get over my feelings of betrayal. Moreover, Kate's problems, which had seemed so "tragic," suddenly seemed more manageable.

Alex has been off chemotherapy for two years now, and no one would ever know she had been sick. She's bright, beautiful and active. She has been a true blessing to the whole family. Kate is now in preschool. She is progressing, albeit slowly, and has become a joy to us.

Friends constantly ask how we have managed "so well." I'm sure you also hear comments like this: "I could never do as well with your situation. You are so brave." As you probably realize by now, that type of sentiment is bunk. You deal with things because you have to, not because you want to. But look around—in the papers, on "IV and in the lives of your friends. Unfortunately, tragedy and hardship are not unique to you and your family. Have courage, keep your sense of humor and keep your faith. We will keep you in our prayers.

124

A.S.T., Arizona

## A.S.K.

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## kole models

## Alvin Law, 35, is a motivational speaker who runs his own business, AJL Communications, with his wife, Darlene. In the past, he has worked in both television and radio broadcasting. He has also appeared on the television series "The X-Files," where he played the role of an "armless preacher." Alvin and Darlene live in Regina, Saskatchewan, Canada with Vance, Alvin's 10-year-old son from a previous marriage.

Alvin was born without arms after his mother was given the drug thalidomide during her pregnancy. Thalidomide, a drug prescribed for morning sickness in Europe and Canada in the late 1950s and early 1960s, was eventually found to cause an increase in births of children with limb anomalies. In

1962, thalidomide was taken off the market.

The following was adapted from an interview between Law and Exceptional Parent intern Amanda Young.

hen I was born, the doctors told my parents I would require full-time care for the rest of my life. My parents decided they couldn't cope with that kind of responsibility. They were a farm family, and they made a decision about what was best for the farm. They left me in the hospital to be adopted.

The couple who adopted me were already grandparents. They decided to become foster parents because their two sons were no longer living with them. They were lonely and my mom, Hikla, was too old to have another child. My dad, Jack, worked long hours as a mechanic. Although they didn't have a lot of money, they sure had a lot of love. That sounds like a cliché, but they were just very special people.

Perhaps more importantly, they were practical people. They didn't shepherd me from hospital to hospital trying to find a "cure." They simply decided I was going to have to work things out myself.

I remember the first time my mother asked me to do the dishes. I looked at her and asked, "How?"

Her answer was simple: "Well, you're the one without arms--you figure it out."

#### **Public school**

My parents fought to have me attend the public school across the street from my house. It wasn't a political cause—they weren't trying to change the system. They were simply being practical. Why go across town to a special education school, when you could just go across the street?

I never recognized the magnitude of my going through the regular school system. School was school, cowever,

## **Alvin Law** Feet first!



Alvin at 18 months-ready for a cold winter!

I understood a little bit of the politics because I was in the principal's office the day he told my parents that I could attend. At that moment, I remember feeling I didn't belong. But at the same time, I was thrilled to go

to the same school as my friends.

I was one of those kids who was often left out on the playground. I couldn't do all the rough stuff—tackle, fight, climb trees. My friends never deserted me, but they weren't going to push the other kids to let me play. So my sporting activities were based in my backyard. I played soccer, which was a natural for me, but it wasn't a big sport back then. I played hockey in the winter, I would just kick the puck. I spent each summer exploring, swimming and playing in the lake at our summer cabin. Those experiences became more important to me than sports.

#### Feet first

During my childhood, I went to rehabilitation hospitals every year from the time I was three until I was about 14. Doctors focused on training me to use artificial arms. Theoretically, these arms would work as well as real ones, but I became truly handicapped when I tried to use them. The prosthetic arms felt foreign-uncomfortable and heavy. They made me feel unlike myself. Because I had never lost my arms and hands, I had no instinct for using them. In the end, what I was born with worked

best for me. In fact, I was always pleased that I could do things with my feet that other kids did with their hands. I liked chemistry class because of the lab work. It was a point of pride that I never had an accident. My parents pushed me to be extra good at doing things with my feet. People notice it to this day. I'll be on an airplane and they'll hand out those little bags of peanuts. Most people



"During high school, music was the biggest part of my life," says Alvin. Using a special chair equipped with clamps to hold the instrument in place, 17-year-old Alvin used his feet to rlay trombone in the Yorkton City Band.

will offer to open them for me. But I have no problem opening those bags. I work hard at trying to be dexterous. I'm a perfectionist; I make sure I don't have any accidents or little spills.

#### Joining the band

Looking back at my high school years, I realize that relationships with friends and girls were too important to me. I felt I needed many friends and a strong dating life to be

accepted. The problem was that it never happened. I had good friends here and there, but our friendships became very complicated in high school.

The biggest part of my life during that time was the school band. When I was 11, I scored very highly on a music aptitude test at school. My mom got a phone call from the band director, saying, "We just can't let a musician like this slip by. We want him in the band."

My mom's immediate response was, "You don't know him, do you?"

Surprisingly, they invited me to join the band even after my mother explained that

I had no arms. I learned how to play the trombone. The band director built a chair for me, with rods and clamps that held the trombone. I moved the slide with my right foot. In 1978, I actually ended up being rated one of the top ten high schoo! jazz trombonists in the country. I played in an all-star band that year and won several competitions.

I didn't become a skilled musician overnight, however. I worked very hard at it. Music became my biggest outlet—the trombone, the drums on the side, and singing in choirs.



A new family: Alvin, Darlene and eight-year-old Vance Law. Alvin and Darlene were married in July 1992 in Yorkton, Saskatchewan.

On Saturday nights when other kids went out, I stayed home to practice. I didn't date. I didn't party, I had the trombone.

I blamed all of my social problems on my disability. Without question, high school was the most difficult period of my life.

#### Independence

After high school, I went to Mount Royal College in Calgary, Alberta, about 600 miles from where I grew up. I had decided to go into broadcasting, and Mount Royal was one of the two best broadcasting institutions in Canada.

I was not looking for education as much as independence. Mount Royal was perfect—it was a small college with about 4000 students. I made a commitment to myself that I was not going to worry so much about rejection, friends and everything that had seemed so important to me in high school. And it worked. Before I knew it, I was not only accepted by my peers, but I had started to date and go to parties. I became a bit of a social butterfly, like a lot of college students. But not at the expense of my marks—I graduated with honors.

continued on page 28



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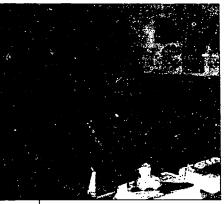
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Circle #63

Circle #107



Newlyweds Alvin and Darlene posed for the camera at every turn. Here they make the first cut into their wedding cake.

continued from page 27

Getting started
In 1980, I found a job as
a radio disc jockey, and
I worked in radio for
almost a year. I didn't
stay with it long
because I was presented
with an opportunity to
become a lecturer during the International
Year of Disabled
Persons. A friend of
mine had received a

grant to do a year of programming for the schools. He couldn't take on the project by himself, so he asked me to help him.

I had learned communication skills in college, but I discovered my ability to lecture when I went on the road to speak to students. I'm always amazed when people say, "I could never get up in front of a group and talk." That's where I'm most comfortable!

Still, the hardest part about this kind of speaking is remaining honest with myself as I go out in front of audiences and open up my life. I was never an extremely private person, but I still felt reluctant talking about certain things. It was an eye-opener to me that I could do it, and I felt quite proud that people appreciated my doing it. I'd found my niche.

#### Positive thinking

Unless somebody can give me a better job than this one, which is unlikely, I'll probably be a motivational speaker forever. Before I found this career, I felt as if I was subject to society's whims; now I am in a position to bring about change.

I do approximately 250 programs a year in high schools all over North America, primarily in Canada. My speeches address self-image, self-esteem and positive thinking. They are designed like most motivational programs—meant to encourage positive thinking. I believe that if you have a positive attitude, good things will happen to you.

In my speeches, I stress the importance of holding on to the dreams and beliefs we had when we were young. Children are sure they can accomplish anything. When I was a little kid, I didn't doubt myself. That certainty came back to me later on, when I finally got my act together again. People call that kind of self-confidence "maturity." Is that maturity? I don't know. But now that I've been around the block a couple times, I can finally recognize what's important.

## THE CHAIRSCHOLARS FOUNDATION, INC.



would like to congratulate our first four CHAIRSCHOLAR College Graduates:

Wanda General

- Valencia Junior College, Orlando, FL

Amy McKnight

- Michigan State U., Lansing, MI

Joel Post

- U. of South Florida, Tampa, FL

Vi Vorsane

- ITT-Engineering, Dayton, OH

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We also welcome our four new CHAIRSCHOLARS who will be in college this Fall:

Katie Cubbage

- East Carolina U., Greenville, SC

Erika Medina

- Gonzaga U., Spokane, WA

Ellen Stern

- State U. of NY, Farmingdale, NY

Joey Thomas

- U. of South Carolina, Columbia, SC

These students will join six other CHAIRSCHOLARS enrolled in schools throughout the U.S. - Best wishes to them all!!!

The trustees thank all of you for helping these courageous young men and women pursue their dreams with your kind help.

Scholarship applications for the **CHAIRSCHOLAR** Program can be obtained from "Doc" and Alicia Keim: 17000 Patterson Road #38, Odessa, FL 33556. Deadline for filing for college, Autumn 1996 - January 15, 1996. High School Seniors and College Freshmen in wheelchairs should apply.



## amiliar Faces



Lauren Light, 12, of Chesterfield, Miscouri and her brothers, Josh, 9, (left) and Aaron. 11, (right) enjoyed lighting the meno-

rain candles during their family's 1992 Chanukah celebration. In addition to her love for holidays, Lauren also enjoys playing basketball, singing and dancing. Lauren's mom, Diane, describes her daughter as "beautiful, funny and very sociable." Lauren has a seizure disorder and mild mental retardation.

**Last Christmas** found four-monthold Vincent **Ficarrotta** posing amidst a plenitude of poinsettias! Mom Mary-Kay reports that Vincent loves to play with his Casio electronic



plano, but his favorite "toy" is his four-year-old sister, Jeena. Vincent, who lives in West Babylon, New York, has multiple physical disabilities including arthrogryposis, a condition causing severely decreased joint mobility, and a variety of limb anomalies.



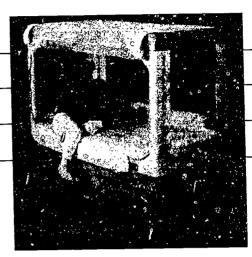
Is that a two-tone dog bone? Mom Penny caught twoyear-old Kyler **Aubrey** sharing his Christmas candy cane with his 'guardian angel," Molly. Kyler has developmental delays, but has not

een diagnosed with a specific disability. His mother writes that Kyler is a happy child whose "smile is worth a thousand words." The Aubreys live in asboro, Georgia.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was en, address and daytime phone number, and identify everyone in the oto. If you like, you can also write a few sentences about your child. en look for a familiar face in an upcoming issuel

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lare and Ron Broos of Cottage Grove, Minnesota had

raised five children of their own. They felt more than ready to become grandparents, and were thrilled when their first grandchild, Andy, arrived in August 1985.

Andy's physical development seemed fairly typical, but he cried a lot and never slept through the night. Still, Clare and Ron were anxious to have Andy spend a night at their house. How tough could one night be? But Andy would not go to sleepnone of Grandma's or Grandpa's tried and true methods worked. At 2 a.m., Clare and Ron raised the white flag; they called Andy's parents to come pick him up.

At Andy's two-year

check-up, his doctor told the family that Andy had developmental delays "too severe to test." A few years later, he was classified as having pervasive developmental disorder (PDD), with impairments of social interaction, verbal and nonverbal communication and imaginative play.

Andy's grandparents were devastated. "We didn't know where to turn," Clare remembers. "We gave all the support we could to our children, but we had no one to turn to ourselves. We called around to see if any support was available. Someone referred us to the Grandparent Program at the PACER Center in Minneapolis. It was such a relief to find someone doing something for grandparents."

#### A unique position

Grandparents of children with disabilities often find themselves in a unique position. While expected to provide emotional and practical support to help their adult child adjust to the demands and stresses of having a child with a disability, grandparents may be struggling with their own uncertainty and grief. Lacking direct access to the information resources available to their children—doctors, social workers, therapists and other families of children with disabilities—grandparents may not receive sufficient information about the nature of a grandchild's disability or its effects. Many grandparents also feel an intensified level of sorrow; they grieve not only for themselves, but also for



# Grandparents Have Special Needs, Too

by Jane Johnson

Members of the PACER Center Grandparent Program enjoyed a grandparent-grandchild picnic in June 1995.

their adult child and their grandchild.

Many communities have services to meet the needs of children with disabilities and their parents, but very few ever consider the special needs of their grandparents. But grandparents have special needs, too. As Joyce Ratner, PACER Center volunteer and first co-chairperson of its Grandparent Program, puts it: "Being the grandparent of a child with special needs is the same as being the grandparent of any child, but it's different, too-right from the beginning. The birth of a child with disabilities introduces uncertainty and mixed

emotions into an event that usually reassures grandparents that their family is continuing into the future."

#### Planning a network of support

In 1990, at the PACER (Parent Advocacy Coalition for Educational Rights) Center—the Parent Training and Information center (PTI) for parents of children with disabilities in Minnesota—advisory board member Sara Lieberman first raised the topic of grandparents during a discussion about ways to expand PACER's supports for parents. Lieberman, the parent of an adult son with a disability, recalled that her son's grandparents had also struggled with issues related to his disability. If PACER could help to meet some of the special needs of grandparents, Sara told the board, these grandparents could become a valuable source of strength and support to their adult children facing the day-to-day demands of raising a child with disabilities.

There were few program models to be found, so PACER Co-director Paula Goldberg decided to draw on the Center's experiences with parents. Time and again, PACER had seen that parents of children with disabilities became able to provide valuable support and practical advice to other parents once they became knowledgeable about disabilities and available services. Extended networks of support were a source of strength to parents; maybe the same model could work for grandparents.



#### Pictures and stories

In 1991, PACER held two workshops to introduce its Grandparent Program. More than 150 people from throughout the state attended. The first workshop focused on ways to organize support groups for grandparents; the second dealt with issues of grief, loss and finding new dreams.

Following these workshops, a group of grandparents organized to become the Program's advisory board and planning committee. The planning committee surveyed grandparents to ensure that future activities would be responsive to their needs. Based on the information collected, they began to develop workshops, small support group meetings with educational and support components, and a grandparent-tograndparent telephone network to provide support to new grandparents of a child with a disability.

The Grandparent Program philosophy asserts that grandparents are their own best resources. As one grandparent said, "I was overjoyed to walk into a roomful of people who understood how I felt without explanation. No one knows as well as someone who's been there."

The Grandparent Program support group meets throughout the year, led by grandparents who have been trained as group facilitators, with PACER staff members serving as information resources and consultants. Meetings have covered topics such as inter-generational communication, relationships between grandparents and their adult children, ideas for summer activities with grandchildren and much more. Many support group members have become advocates to maintain or improve the services their grandchildren receive. They offer encouragement, comfort, humor and advice to one another.

Above all, these grandparents enjoy doing what grandparents do best--proudly sharing pictures and stories of their grandchildren. A grandparent-grandchild picnic in June 1995 gave members a chance to match the real live grandchildren with the pictures and stories their proud grandparents had shared.

Members say the support group has reduced their sense of isolation. As one member told PACER, "This support group helped me get out of the closet. I now realize I'm not the only grandparent whose grandchild has a disability. I feel okay about asking for help to understand her needs and abilities."

Another : ember expressed how the group has enriched her relationship with her grandson, "The support group has relieved me of one of my biggest worries—that of concentrating solely on my grandchild's disability. Now, I see the child first, not the disability." EP

Jane Johnson is the coordinator of the PACER Center Grandparent Program. For a brochure or more information about the Grandparent Program, PACER's other projects or a free publication list, contact PACER Center, 4826 Chicago Ave. South, Minneapolis, MN 55417-1098; (612) 827-2966, V/TTY: (612) 827-3065, fax; e-mail: mnpacer@gteens.com.



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## ndparents

## "Normal" *A Grandmother's Point of View*

by Diane Bennett



he situation was out of my control. My daughter and her husband were not in any posi-

tion to have a child, let alone a child with special needs! I wasn't ready to be a grandparent, and I definitely wasn't prepared to welcome a baby with missing genetic information. Why was this child determined to join us? If I had to have a grandchild, I wanted one with all the "normal stuff." I had raised my daughter with "normal stuff" in mind.

Images of normalcy surround us to the point that most of us take "being normal" for granted. Sure, once in awhile you see a child with "problems," but it's easy enough to glance away. Healthy, happy children make their way into our hearts on many of our favorite TV shows; baby magazines are full of how-to articles for parents of children who are growing and developing in typical ways; "normal" is implied in the advertising and packaging of each appealing baby product. This was the "normal" I knew. This was the "normal" I had expected. This was the "normal" I passionately wanted for my daughter-and, yes, for myself.

#### Diagnosis

"Deletion," the doctor told us.

"Mackenzie has a deletion on the end of the long arm of her twenty-second chromosome. She is genetically different from other children. You might say she is missing a small but important part. Her condition is quite rare. You will have to be patient and see how she progresses." He looked down at his notes and began nodding us toward the hall, then added, "It is



I DON'T KNOW IF
MY LIFE IS "NORMAL,"
BUT I DISCOVERED
THAT WHEN I WAS
READY TO CHANGE,
SUPPORT WAS AVAILABLE
AND POSSIBILITIES
SHOWED THEMSELVES
IN A BRIGHT,
NEW WAY.

Diane Bennett holds her 14-month-old granddaughter, Mackenzie Lopez.

difficult to determine the extent of her developmental delay. I'm sorry, but I don't have that much information to give you."

Mackenzie's diagnosis—and the little bit of information the doctor could provide—brought some relief, but it brought something else, too. I became increasingly sensitive to the frequency with which regular growth and development surrounded me, blasting me at every turn.

A simple trip to the grocery store threw me into emotional turmoil. By the time I hit the cereal aisle, I would have already wheeled my cart past scores of young, attractive parents with active, normal, adorable children.

It made me sick! I painfully resented their good fortune and health. Where was my wallet full of cute snapshots of my normal

baby granddaughter? Why was my daughter beset by never-ending doctors' appointments, teary phone calls and an endless trail of paperwork?

#### Outside the boundaries

I had been carelessly tossed outside the boundaries of that safe world inhabited by my peers. I was living in a place where everyday events took on sinister shapes:

Just another shopping trip with a friend—my turn to drive so I swung by to pick her up. As she slid into the seat next to me, she excitedly said, "Look what Laura and Pam made in their Mommy-and-Me class."



She was proudly wearing a pink tee-shirt with imprints of baby feet and the caption "I walk all over Grandma."

The rational part of me knew it was just a cute, silly teeshirt, but the rest of me felt personally exposed and insulted. My heart jumped, my eyes welled and I quickly blinked back tears.

"How insensitive to flaunt that in my face!" I thought. "I'd love Mackenzie to walk all over Grandma! I'd love Macky to walk at all!"

#### Facing my fears

Months passed. I was constantly tired. I was always on the verge of tears, ominously aware of a vague cloud of fear that hovered in my mind. "Great," I told myself. "It was bad enough my daughter had a child with a disability. Now she's got a crazy mother, too."

Something had to change. The situation was not going to change, but I could. Other parents and grandparents had met similar challenges head-on. It was time for me to face my fears.

I began by volunteering in special needs classrooms and recreation programs. I fed children, took them out into the sun, turned on music tapes, wiped faces and diapered bottoms. I lifted kids into standers and positioned them on horseback. I listened to their assorted squeals and giggles. I saw a lot of grins.

I "hung out" at Macky's school, where my granddaughter and other infants rolled on the mats, played with the toys and received physical therapy. I rubbed elbows with courageous parents and skilled professionals.

Somewhere during this time, I heard the phrase, "Raise the child not the disability." I liked the tone of that. It jarred my perceptions. It felt like a place to start.

Cleaning out the "thought boxes" Before Mackenzie's birth, I could have told you exactly what I thought about almost anything. My rigid ideas fit nicely into sealed "thought boxes." I had empathy for the "special situations" of others, but when I came up against something that would not fit, something I did not want, something I could not change, it wreaked emotional havoc.

Mackenzie's arrival prompted some real cleaning of my "thought boxes." I had to learn to look for the whole rather than the parts, the similarities rather than the differences. I had to learn to see the child, not the disability.

Eighteen-month-old Mackenzie munches a cookie while showing off her newlyacquired skill of sitting independently.





Enjoying a day at the beach, Mackenzie, 17 months, "adjusts" Grandpa Bruce Bennett's swimming goggles.

In the process, I became the "normal" doting grandmother:

Both Mackenzie and I are all smiles and
giggles as I hold her. She reaches out, first
touching my nose, then my lips. Her hand
brushes my cheek. One more stretch and
she has the prize—Grandma's earring!

I've learned that "being different" coexists with "being normal." Love, joy, frustration, hope, anger, confusion, change, worry, playfulness, sorrow—these emotions are part of every parenting or grand-parenting experience. No matter what the situation, you do your best. You love. You wonder. You hope. You hold tight to courage. You develop faith.

I see my daughter doing these things and I am proud. I am moved by her love and early-found maturity. And I am captivated by my granddaughter, who is beautiful beyond words.

I don't know if my life is "normal," but I discovered that when I was ready to change, support was available and possibilities showed themselves in a bright, new way.

Mackenzie came into my world and changed everything. And I mean everything. Not just practical realities like care and money. Mackenzie has also given new meanings to more abstract realities—like what is "normal," what is fair, and what is possible. **EP** 

Diane Bennett lives with Richard Cheek in San Clemente, California. Diane and Richard enjoy spending time with their extended family, which includes four adult children, a dog, a cat, a desert tortoise and two chickens. Diane recently returned to teaching at Westmont Elementary School in Huntington Beach, California after taking a two-year leave to be with her daughter, Molly, and granddaughter, Mackenzie.



. P U 🗓

## READERS TALK ABOUT: **Family**

## THE IMPORTANCE OF FAMILY

was an only child, and accustomed to my privacy. Then I married Rich, the oldest of seven children. It took a lot of getting used to.

Rich's family was very close, and there were

so many of them-five brothers, one sister, aunts, uncles, grandparents, great-grandparents, cousins, great-aunts and great-uncles. There were so many I couldn't keep them 🛷 straight. When I was growing up, there were Mom, Dad, Grandma and me. We saw the rest of the family once in a while. But with my husband's family, it seemed like there was always some event happening, and everyone would be there. It was more than a little overwhelming.

When we started having our own children, my ideas began to change. Thanks to Rich's large family, someone was always available to babysit. And since Rich's youngest brother was just eight years old, he was always willing to play with the

kids. A large family was starting to look like a better idea. But it wasn't until our youngest child was born that both

Rich and I realized the true value of a large, loving family.

We invite you to contribute to the discussion in future issues of Excepnown. PARENT, In upcoming months, readers

READERS TALK ABOUT:

 Children's experiences at summer camp (March issue; describe Jenuery 1)

· Family vacations (April Issue; deadline

will be talking abouc

- · Parenting twins when one or both have disabilities (May issue; deadline March 1)
- . Twenty-five years of Exceptional Parent: For our anniversary Issue, tell us what the magazine has meant to you (June issue; deadline April 1)

Write to: Readers Talk, Exceptional Parent, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).



Seven-year-old Rvan Carew had a front row seat at his aunt's wedding two years ago. With him were Poppy and Nana Jones and sister Amy, 10.

Ryan was born five weeks premature, and had a very difficult birth. After being transferred to a hospital specializing in infant care, he was diagnosed with hydrocephalus (fluid on the brain. Poctors told us he would be in the hospital for quite a while.

From day one, our families pitched in to help. Grandparents took care of our two older daughters, Maggie and Amy. The

4. O 11 1

girls spent most of the next six weeks at my parents' house, and Rich's parents cared for them when my parents went to visit Ryan.

All of Ryan's grandparents came to visit as often as pos-

sible. These times were a great source of support. I will never forget the first time my mother held Ryan. He was hooked up to all kinds of tubes, but grandma could see nothing but her beautiful new grandson. I can still see her holding him as she sat in a rocking chair next to his bed. She rocked him and sang an Irish lullaby. I could feel the immediate bond that formed between them.

This past year has been an especially hard time for Ryan, and for the rest of the family as well. Ryan went from an active, vivacious seven-year-old to a child who could not get out of bed. He was having multiple seizures, and trouble with his shunt (the tube placed in his head to drain the extra fluid

off his brain). Ryan spent two months in the hospital, and had five new shunts put in. As each one failed, he became increasingly weaker.

Our families rallied around us again, doing whatever they could to help. Relatives stayed with Ryan whenever Rich or I couldn't be there. They brought foods he liked to tempt him to eat and talked to him several times a day on the phone. Family members also took care of the girls, keeping their everyday lives as normal as possible. Those family members and friends who could not visit the hospital sent endless cards and letters. Ryan was thrilled by all the mail.

My perspective on extended family is much different than it once was. I now wonder how we would ever survive without them. They surrounded us constantly while Ryan was in the hospital, and far from feeling overwhelmed, I could only say, "Thank God they're here." Being part of a large family is great; I'm so glad our children are growing up with an intimate knowledge of how very important family is.

> -Kathy Carew West Haven, Connecticut

## LOVE + INCLUSION = FAMILY

hen our two girls were first diagnosed with Down syndrome (Melinda, 11) and cerebral palsy (Mary, 8), everyone in the family initially reacted with shock and denial. This was especially true at the

time of Mary's diagnosis; nobody could believe that one family would be dealt two children with special needs.

I guess our feelings were pretty normal. But it didn't take long for us to feel the love of our relatives and friends. This love—so strong it felt like a warm embrace—

During an overnight visit to the home of Grandma and Grandpa Ennis, 11-year-old Mary spends some time working with Grandpa on his woodcarving hobby.

is what helped us through those long first days. And soon the days were not so long. As the years have passed, our family and friends continue to share our moments of happiness as well as sorrow.

My husband's mother, Grandma Hettel, has always had a very special relationship with the girls. She is just old enough to be from a generation in which "different" children were kept out of sight. She is thrilled that this is no longer the case; she takes great pride in being a part of all the girls' activities and showing them off to her friends. Her arms are always open for big hugs from Melinda and Mary. Our family feels so lucky to have our wonderful Grandma Hettel.

My parents,
Grandpa and
Grandma Ennis,
have always been
my strength. Since I
am their "little girl,"
I can still cry in their
arms. Of course,
they are also among



Grandma Hettel celebrates a birthday with (from left) Mary, 4, and Melinda, 7.

the first to hear our joys as well.

My parents have a precious relationship with Mary and Melinda. Ho one tells a story like Grandpa Ennis. The girls love to conddle in a big chair with him to hear "just one more." ( randma Ennis has a lot of energy. She can spend all day playing with the kids. My parents also love to have the girls spend the night at their house. They do this on an individual basis so these times are very special.

When it comes to our family and friends, the one constant—besides love—is inclusion. There is never a question about whether our girls will be welcome at any gathering. Our family is always well-received, made comfortable and included in all the action.

Our extended family and friends make us a fortunate family. To all of them, I humbly say, "Thank you!"

—Julie Hettel Marseilles, Illinois

## PAPA AND NONIE

ommy's relationship with his Papa and Nonie, Norman and Jacquelin Janson, involves a bond that is difficult to put into words. I know, because I've already tried to write this several times.

Eleven-year-old Tommy, the second of our four children, has mental retardation. Because of his developmental delay, he still has some of the fears common to very young children. For example, the roaring dinosaurs at the Science Center terrify him. So when Papa and Nonie bring the other children to the Science Center, Tommy just can't go along.

One solution might be to leave Tommy out completely. Another would be to skip activities in which Tommy cannot participate, even if they are things the other children enjoy. Instead, Papa and Nonie decided that when the others do something Tommy doesn't enjoy, he should get his own special outing later, to MacDonald's or to the mall—two of his favorite places. At first this solution seemed too simple; Papa and Nonie thought they should do more. But they soon realized that the little trips were what Tommy wanted and enjoyed the most.

Of course, there are many places Papa and Nonie can bring

all four children.
And our other three children also have opportunities for individual time with Papa and Nonie.
But Tommy and his grandparents are especially close.

I can see the love and trust on Toniny's face as I watch him sit by the window waiting for Papa and Nonie to come pick him up for one of these



Noman and Jacquelin Janson (aka "Papa" and "Nonie") celebrated their fortieth wedding anniversary with their grandchildren, (clockwise from left) Tommy, Stephen, Jimmy and Ellen.

special outings. "Papa come pick me up," he repeats (about a million times) before they finally arrive. If he knows about a visit further in advance, he tells everyone he sees, even grocery store clerks. "Papa and Nonie coming Sunday," he

More Family contrined on page 36



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DECEMBER 1995 / EXCEPTIONAL PARENT . 35

continued from page 35

delightedly announces to the world.

When we plan family gatherings, Tommy tells me, "Papa and Nonie come." They are always first on his guest list. When they arrive he runs out to greet them before they even get out of the car. Tommy is always ready to show them his latest video game. And Papa and Nonie are always ready to watch and listen.



Papa lent a hand with the games at Tommy's sixth birthday party,

Tommy knows that Papa and Nonie are two of the many people who love him. He loves them, too. Most importantly, he knows he can count on them. Seeing them together—Papa, Nonie and all four children—makes us very glad there's a Papa and a Nonie in our lives.

Susan Moore Black Jack, Missouri

## GRAMMY'S FAVORITE



hen we were children, my two brothers, my sister and I always tried to figure out which of us was my mother's favorite. "We know you have a favorite," we'd tell her. "Who is it?"

My mother always insisted she loved us all equally. Now that we're grown and have our own families, we realize that's true. Mom really doesn't play favorites... Well, maybe with one exception—everyone knows she has a special place in her heart reserved for her six-year-old

grandson, Bryant.

My sister and I got pregnant for the first time within months of each other. Lynn was a few months ahead of me and seemed to be having an easier pregnancy than me. Still, it was wonderful to share this experience. We enjoyed many ice cream sundaes and daily chats



Grandmother Elaine Deane doesn't let a few tubes get in the way of a good snuggle with her newborn grandson, Bryant Paquette.

about what we had for breakfast—usually something fattening! I was with her when she gave birth to her daughter and looked forward to her being in the delivery room with me as well.

It was not to be. Bryant was born by emergency c-section—born with so many problems we could hardly keep track of them all.

My entire family, everyone from my 80-year-old grandmother to my cousins, rallied around to provide comfort and support. My sister visited the hospital faithfully, even though she lived more than an hour away and was caring for a newborn of her own.

My mother, however, was my most constant source of strength. Although my husband had to work every day, I never made that long drive to the hospital alone. During the four months Bryant spent in the neonatal unit, my mother accompanied me to the hospital daily, providing both emotional and physical support. She backed me up the day I sat in a meeting with medical professionals and fought to bring Bryant home. The doctors finally agreed, although they were not at all sure we could handle an infant who needed round-the-clock nursing care.

Bryant came home, on full life-support, to a miniature intensive care unit in our small apartment. During his first week home, he had a cardiac arrest—just the beginning of a traumatic first year we might not have survived without the support of my parents.

Bryant's surgeries have taken us throughout our home state of New Hampshire, and as far away as Pennsylvania and Tennessee. My mother has come with us every time. Along with her concern for Bryant, she always takes the time to make sure I'm doing okay. And it hasn't been easy. Now that I'm a mom, I can see how your children's heartbreak truly becomes your own.

Perhaps most important has been my mom's desire to really *know* Bryant. She has learned to care for his every need—from suctioning his tracheostomy to feeding him through his g-tube. But beyond his trach, wheelchair, leg braces and on-going facial reconstruction, my mother knows and loves Bryant for the unique little person he is. She is proud to be his grandmother and doesn't miss an opportunity to let everyone know it!

Grammy and Grampy Deane look on as 18-month-old Bryant plays with his "spare" CPAP (continuous positive airway pressure) valve. Bryant, who remained on full life support until the age of three, thought his CPAP valve was a great toy. To allow the real one to do its job, the family always kept a spare for him to play with.



What can you say about that kind of unconditional love? My mother would argue that one just can't help love Bryant and, of course, I would agree. But the stark reality is that many people-grandparents included-just can't deal with a child who has a disability. We are extremely fortunate to have both of my parents, whose love for Bryant is manifested every day.

When other grandparents brag



Six-year-old Bryant listens to a story read by Great-Grammy Mary Labrie (left) and Grammy Elaine Deane (right).

about the achievements of their "normal" grandchildren, my mother doesn't wait a minute to chime in with Bryant's latest accomplishments. Perhaps no one would really notice if she casually left Bryant out of these conversations. After all, she has three other "perfect" grandchildren. But to her, Bryant is perfect—and maybe even her favorite!

> –Cheryl Paquette Manchester, New Hampshire

### BEST FRIENDS

Hoping for a "photo op," the local media turned out at the day camp for children with disabilities. As counselors helped children bait fishing hooks beside the lake, a reporter from the local television station asked if anyone was going to catch a fish.

"Sure thing," Bumpa told him. "Stay right here. Adam is going to catch one in no time!" To everyone's surprise but Bumpa's, Adam caught his first fish within two minutes just in time for a camera crew to film him for the local news that evening.



On summer vacation, Bumpa Bob Slagen and Adam Voisin, 3, do their morning stretches in a lawn chair in front of the cottage.

dam is my three-yearold son. who has cerebral palsy, and "Bumpa" is my stepfather and Adam's best friend, Bob Slagen.

When Adam was born ten weeks early, we were told that his grade I brain bleed was not serious enough to cause any damage. The doctors said he'd catch up in no time. Eighteen months later, when he still couldn't sit unsupported, the doctors changed their prognosis and diagnosed him

-Lisa Voisin Muskego, Wisconsin

Bumpa has taught A Jam how to fish, how to play his toy drums and how to draw a circle. He's also taught Adam the meaning of "coffee klatch"-of course, Adam drinks juice in lieu of coffee. I never have to be concerned about my underweight son consuming sufficient calories. Bumpa feeds Adam a full-course meal at noon. (Bumpa doesn't call it lunch; it's "dinner.")

Bumpa is so incredibly biased, it makes my heart melt. Every time, I start feeling bad about Adam's inability to walk, run or ride a bike, my stepfather is quick to pick me up. "That kid is the smartest three-ye-yr-old around," he asserts. And then he'll tell me about some other three-yearold he knows who isn't talking as well as Adam or can't

even spell his own name. I sometimes wonder if Bumpa quizzes every threevear-old he sees!

I don't think I could ask for a better Bumpa to be at my son's side. These two "peas in a pod" are a fine example of what best friends are. The only thing separating them is 60some years.

The next best thing to being there: Adam loves to talk to Bumpa on the phone. On this night, Adam called to tell Bumpa what Mom was making for dinner.



with cerebral palsy.

As is true for most working mothers, child care became a major concern for me. Adam and I had gone through three babysitters when Bumpa, who is retired, asked if he could take over.

I couldn't have asked for a better situation for my son! Bumpa and Adam always find something fun to do together. Sometimes they go to the local shopping mall just to ride the elevators, one of Adam's favorite activities. Bumpa and Adam ride all eight mall elevators, then come home.



DECEMBER 1995 / EXCEPTIONAL PARENT . 37 1654

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## "Project Cousins"

## Discovering the joys of family

by Ann Darby

s the oldest of six children, my husband, Michael, was used to the noise and chaos of family gatherings. But I was an only child, and finding my place among my husband's closeknit family was an adventure and a challenge. Gradually, I came to love and enjoy the company of Michael's brothers and sisters, as well as the hectic life of a large family.

Over the years, our extended family grew to include six spouses and 10 grandchildren; each new addition was welcomed with enthusiasm. The family shared our joy when we adopted our son, Kevin. And, although we lived miles apart, they shared our pain when Kevin was diagnosed with severe cerebral palsy.

Even though family gatherings had always been times of excitement and joy, part of me began to dread these get-togethers. These events had become times of "what ifs" and "if onuy:" for me. As Michael's brothers and sisters shared the highlights of their children's lives, Kevin's accom-

plishments seemed to pale by comparison. One child had played a harp solo at church; another had been placed in the gifted program at his elementary school; a third was going to be in a dance recital. What was I supposed to say about Kevin? That he could now take a few steps without falling? That he had learned to pronounce a new word?

It was equally difficult to watch Kevin try to talk or



Spending a weekend at Grandmother's house are (from left) cousins Jaclyn, Lauren, Jason, Darby and Kevin.

play with his cousins. They weren't unkind; in fact, they were always very nice to Kevin, but they quickly tired of making the effort required to communicate with him and moved on to other activities. Kevin didn't seem to notice as much as I did. He just attached himself to that day's favorite uncle, seemingly content to spend his time with the adults.

"Project Cousins," was the result of this brainstorming.

We decided to invite each cousin in Kevin's age group to visit us for several days during the coming summer vacation. We planned lots of fun activities for these visits—swimming, boating, fishing and riding Kevin's four-wheel, all-terrain vehicle.

In the comfort of his own home, we hoped

our son would open up and talk to his cousins. Our goal was that Kevin and his cousins would discover how much they had in common.

That summer, five cousins spent "mini-vacations" at our home. We shared busy days full of summer fum—picnics, plays, movies and trips to the petting zoo. Just as we hoped, Kevin was able to display

In the spring of 1994, my husband and I started discussing some steps we could take to help Kevin develop closer relationships with his cousins.

Our plan, which we dubbed

At a family gathering over Christmas 1994, Kevin was "one of the gang."
Top: Kevin (right) clowns

continued on page 40

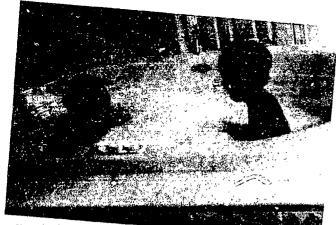
around with Cousins Stuart and

Jaclyn; Bottom: Kevin shares a

moment with his cousin.



Lauren.



Even bath time is more fun when it's shared with a cousin! During a visit to Kevin's house, Stuart (left) and Kevin enjoy a soak in the suds before bedtime.

continued from page 39

his terrific sense of humor and love of life. Everyone seemed to have a great time, but we still didn't know if these "good times" would translate into greater family inclusion for our son.

Joyful holiday gatherings
The big family gatherings at
Thankigiving and Christmas would be
the true test of our project's success.

To our great joy, Kevin and his cousins seemed to pick up right where they'd left off a few months prior. No longer was Kevin hanging around the adults; he was off talking and playing with the other kids.

At one point, Kevin's grandmother complimented one of his aunts on the "kindness" of her son,

who was playing a game with Kevin. Aunt Beth immediately corrected her mother, Stuart wasn't "being kind" and she hadn't asked him to play with Kevin—Stuart was doing what he wanted to do!

All five cousins have asked to come back to our home for visits. Several have already visited; other visits are in the works. The cousins have also included Kevin in trips to ball games and movies, a "cousins-only" party and a weekend at Grandmother's house.

#### Special gifts

In the end, the youngsters in our extended family were not the only beneficiaries of "Project Cousins." By making the time to have Kevin's cousins visit our home, Michael and I made five important discoveries of our own—Meghan, a talented musician growing into womanhood; Morghan, a kind-hearted and strong individual; Lauren, a creative writer and conversationalist; Darby, a nurturing and loving teacher; and Stuart, a bright sports enthusiast and our son's newest "best friend."



Kevin (left) and his cousin, Aaron, grab some potato chips during a "cousinsonly" party.

In helping Kevin and his cousins get to know each other better, his father and I also got to know our nieces and nephews in a fresh, new way. We are thankful for the special gifts each one brings to our family.

Ann Darby lives in Beckley, West Virginia with her husband, Michael, and son, Kevin. Ann is a preschool teacher and Michael manages a Comfort Inn. Kevin, 14, attends Mt. Tabor Christian School in Beckley, where he is in seventh grade.

## Listen Up Parents!

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Circle #14

## **Getting Started**

by Frank L. Brunetti



state planning always involves difficult decisions. The process is even more complicated for those families who must be concerned with the care, comfort and well-being of a child with disabilities, especially if it is clear that

the child is unlikely to be able to provide for his or her own support or make mature day-to-day decisions. Such parents often worry about who will care for a son or daughter after their deaths; they also worry about ensuring that the child's needs will be provided for financially.

To begin the estate planning process, parents must focus on two tasks. The first is to perform an "inventory." The second is to retain an attorney with expertise in estate planning for children with disabilities.

#### The inventory

An "inventory" involves gathering and putting into order the most important documents that your fiduciary will need for the care of your child. (A "fiduciary" is the person you have selected as the personal representative of your estate, such as an executor, a trustee or both.) This inventory, which, for ease of reference can be kept in a three-ring binder, will include the following sections:

- Part I: The Profile—The profile should cover important information about the child's educational, therapeutic and medical history. It should include names, addresses and phone numbers for all the child's doctors, therapists and other service providers. It should also include key medical records, along with the names and dose so fall current medications. Finally, the profile should offer a complete description of the child's disability, and its likely effects on the child's life, both now and in the future.
- Part II: Documents—This section of the inventory should include the following: the child's' birth certificate (original or duplicate

copy), the child's social security number, parents' social security numbers, name and address of the parents' estate planning attorney, name and address of the child's school or day care provider and a guardianship order and/or any other legal documents regarding the legal status of the child in the case that parents become unable to maintain responsibility for his or her care.

• Part III: Living Plan—A plan, written by the parents, describing how they expect the child to live out his or her life. The life plan should cover everything from the child's favorite activities and foods, to a list of friends and relatives—those with whom the child may live, others with whom the child should maintain contact. The plan should also include burial instructions for the child.

The preparation of the "living plan" need not be a "parent-only" task. In many cases, the child and other family members can participate in the process and may contribute useful information and ideas.

#### Finding an attorney

While parents are completing the inventory, they can take steps to find an attorney who has experience in estate planning for children with disabilities. Parent organizations or Parent Training and Information centers may be able to refer parents to a local attorney with expertise in this area. County bar associations may be another referral source.

It is important to retain an attorney with specialized knowledge because estate planning for a child with disabilities requires knowledge of federal tax law; regulations governing SSI, or "Supplemental Security Income," the federal program that pays a monthly stipend to people with disabilities, dependent on income but irregardless of age; state guardianship law and state Medicaid regulations. In addition, some states have enacted special legislation related to estate planning for children with disabilities. For example, certain states allow the establishment of "community trusts," nonprofit organizations that pool

DECEMBE 1993 EXCEPTIONAL PARENT • 41

continued on page 4.1

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#### **Estate Planning Resources**

PUBLICATIONS
Planning for the Future—Providing
a Meaningful Life for a Child with
a Disability

By L. Mark Russell, Attorney, Arnold E. Grant, Suzarine M. Joseph, and Richard W. Fee. This book explains how to prepare a Living Plan, a Letter of Intent and a Special Needs Trust. It explains how to maximize your child's government benefits, avoid probate, reduce estate taxes and much more. Newly revised third edition, 1995, 440 pp. \$24.95.

 Available from Exceptional Paper Library; (800) 535-1910: Order #APO240D.

#### The Life Planning Workbook

By L. Mark, Russell and Arnold E. Grant. A hands-ongrade to help parents prepare for the future security and happiness of their child with a disability after the parents' death, 1995, 272 pp. \$24.95. * Available from Excertow. Parent Library; (800) 535-1910; Order #AP1270D.

A Family Handbook On Future Planning
This handbook helps parents understand and organize a future plan for a son or daughter with mental
retardation includes information on wills, government
benefits, support services, financial arrangements,
guardianships, working with an attorney and other
important areas, Forms, checklists and outlines, along
with completed examples, help parents estimate their
child's needs, and organize their estate to help meet
those needs, 1991: 133 pp, \$16.

Available from The Arc Publications; (817) 261-6003, voice; (817) 277-0533, TTY; Order #10-2.

#### How to Provide for Their Future

By Elizabeth M. Boggs, Ph.D. and The Arc's Insurance Committee. This book provides suggestions for parents, guardians, attorneys and others concerned with meeting the lifetime financial needs of a child with mental retardation. Revised 1989; 46 pages; \$10.

* Available from The Arc Publications; (817) 261-6003, voice; (817) 277-0533, TTY; Order #10-1.

#### NATIONAL PLAN ALLIANCE

The National PLAN (Plan Lifetime Assistance Network) Alkance is a service component of the National "Alkance for the Mentally III. The members of the National PLAN Alkance are independent, not-for-profit PLAN programs that provide care planning services to parenta who wish to continue the care they currently provide into the future when they are no longer able or available to provide such care to "their adult children with disabilities. PLAN programs serve all disabilities.

All PLAN programs ofter three key services: (1) developing a future care plan, (2) helping parents establish the necessary resources to fund the plan and (3) identifying the person(s) and/or program(s), responsible for carrying out the plan. Most PLAN programs also provide services to assist parents with current care needs. PLAN programs are currently operating in the following states:

## ARIZONA Artzona Proxy PLAN Foundation 2241 E Filmore St

2241 E Filmore St Phoenix, AZ 85008, (602) 244-8166

#### CALIFORNIA Proxy Parent Services Foundation 1336 Wilshire Blvd, 2nd Fl Los Angeles, CA 90017, (213) 413-1130

CONNECTICUT
PLAN of Connecticut
PO Box 370312
W Hartford, CT 06137-0312, (203) 523-4951

**PLAN of Georgia** 1256 Briarcliff Rd NE, Rm 421S Atlanta, GA 30306, (404) 853-0494

KENTUCKY Kentucky PLAN 102 E Main St, Ste 203 Georgetown, KY 40324, (502) 863-6609

continued on page 43



# What will happen to your child with a disability after your death?



Easy to read and understand, an essential book, *Planning For The Future*, describes in careful detail the steps that parents should take—from residential, employment and social options to legal and financial elements—to ensure the future quality of life for their child. Highly acclaimed for its original introduction of the Letter of Intent!

#### What are people saying about this book?

"There are many complicated issues you face when you have a child with a disability. It is difficult to find good and accurate resources for many of the problems but when it comes to estate planning the place to turn to is books written by attorneys L. Mark Russell and Arnold Grant. They make even the most complex

problem understandable and easier to solve. This is a "must have" book for parents and professionals dealing with estate planning for people with disabilities."

—FRANK J. MURPHY, EXECUTIVE DIRECTOR, NATIONAL DOWN SYNDROME CONGRESS

"Expert information on this very important often complicated topic. Very valuable for parents and professionals."

-STANLEY D. KLEIN, Ph.D., EDITOR IN CHIEF, EXCEPTIONAL PARENT MAGAZINE

"Planning is this book's overriding feature—no matter what the disability or how small or large the income, if there is a well-considered and thoughtful plan...children with disabilities will have a greater chance of enjoying the best possible health and security. This book is a must purchase for all parents who have children with emotional, physical, or mental disabilities."

-Legal Information Alert

"Planning for the Future is a book we distribute at all Arc events. We have found it to be a great deal of value and very easy to understand for all parents concerned about planning."

—TONY PAULAUSKI, EXECUTIVE DIRECTOR, ARC OF ILLINOIS

"A comprehensive publication which presents an easy to follow approach to addressing vital questions and burning issues that caregivers and consumers encounter. A must for every professional in the field of mental retardation."

—B.R. Walker, Ph. D., Past President, American Association of Mental Retardation

"Using this book is probably the single most important planning step that you can take for your child."

—PROFESSOR KENNETH FRIEDMAN, FROM A REVIEW IN The Association for Persons with Severe Handicaps (TASH) Newsletter Newly available from the authors of Planning For The Future



While Planning For The Future discusses all the options in detail, The Life Planning Workbook is designed as a hands-on workbook to guide parents through the planning process. By completing the various parts of the workbook, parents can put what they learn in Planning For The Future to practical use. The workbook enables parents to: convey critical information about their child to future caregivers; calculate their child's lifetime financial needs; organize their affairs to permit continuity of care for their child after their death; save time and money by preparing in advance to meet with attorneys and other advisors. The Life Planning Workbook can be used separately or in conjunction with Planning For The Future,

To order your copy of *Planning For The Future* or *The Life Planning Workbook*—

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continued from page 41

resources for the benefit of people with severe disabilities. In return for contributions to a community trust, a designated individual with severe disabilities can receive lifelong services such as administration of trust funds, advocacy (for example, participation by community trust representatives in the development of individualized plans developed by service providers) and/or guardianship.

Typically, most attorneys will give a free or reduced-rate initial interview. Parents should go to the initial interview with a specific goal-to determine whether this attorney can properly serve their needs, and for a reasonable fee. To be capable of making this determination, parents need to know something about relevant legal issues before going to the interview. These issues might include the Medicaid "resource" rule (the way their home state considers assets when determining eligibility for Medicaid coverage) and reg-

ulations for establishing legal guardianships in that particular state. This type of information is available through various publications and national organizations.

#### Financial needs and liquidity

Before the estate planning process can begin in earnest, parents must

determine the financial condition of their estate and decide if and to what extent their estate will provide for beneficiaries other than the child with a disability (for example, siblings). They will need to prepare an updated financial statement, as well as a family profile that outlines their particular estate planning needs. For example, if parents' assets include a family-owned business, they need to consider whether the business will be passed on to heirs or be sold. If the business is to be inherited by children in the family, the estate planner must find a way to pass the business on to the designated heirs without its assets being depleted by estate or inheritance taxes. If it is to be sold, sales arrangements should be made as part of the estate planning process.

Many families face the common estate planning problem of liquidity. "Liquidity" refers to cash or the ease with which other assets can be converted into cash. Because treasury bonds can be easily converted into cash, they would be considered "liquid assets." Real estate, on the other hand, would be considered "illiquid."

Liquidity is an important estate planning issue because parents need to determine whether their estate will have enough cash to pay for liabilities such as federal and local estate/inheritance taxes. In addition, if parents hope to set aside funds for the care of a child with disabilities, they need to think about where these funds will come from. Do they need to purchase life insurance, or should they transfer new or existing insurance coverage to an irrevocab'e intervivos trust (a trust established during the lifetime of its creator, which cannot be revoked)?

#### Writing a will

Once these preliminary steps have been completed, parents can begin drawing up a will.

Because many forms of government assistance are denied to individuals with substantial assets. the will must exclude the child with a disability from inheriting or find an alternative way-such as a "special needs trust"to maintain the child's eligibility for benefits and insulate the inheritance from government

claims seeking reimbursement of previously paid benefits. [EDITOR'S NOTE: "Special Needs Trusts" will be the topic of an article in the February 1996 issue of Exceptional Parent.]

Another important feature of the will is the appointment of the executor (or executrix). The executor is the person charged with making sure the will's provisions are carried out. The executor must gather the assets, pay the liabilities, file tax returns and fund any trusts. Typically, the executor will be a family member or close friend. In some cases, particularly with complex estates, the executor may be a bank or trust company. An attorney or accountant usually assists the executor in handling the estate.

If the will provides for a trust, a trustee must be appointed to manage the trust until its termination. While the executor's term will be short-lived, the trustee may serve for years, even decades. Next to selecting a guardian, the choice of a trustee is the most difficult decision. The trustee must have

#### Estate Planning Resources

continued from page 41

MARYLAND LAM of Maryland & DC 912 Thayer Ave

Silver Spring, MD 20910, (301) 587-7815 **NEW JERSEY** 

PLAN of Now Jersey 1275 Bound Brook Rd, Ste 1 Middlesex, NJ 08846-1486 (908) 563-0300

MEN YORK PLAM of New York Park Ave S, Ste 1201 New York, NY 10016, (212) 545-7063

NORTH CAROLINA Life Plan Trust PO Box 20545 Shaleigh, NC 27619, (919) 782-4632

THE O PLAN of Northeast Oblo 3130 Mayfield Rd, Ste GW 112 Cleveland, OH 44118, (216) 321-3611

PENNSYLVANIA PLAH of Pennsylvania 110 W Lancaster Ave Mayrie, PA 19087, (610) 687-4036

**PHODE ISLAND** SST of Rhode Island PO Box 28411 Providence, RI 02908, (401) 464-3060

PLAN of North Texas 3300 W Mockingbird Ln, Ste 723, LB #2 Dallas, TX 75235, (214) 956-9933

VIFIGINIA **Personal Support Network** 100 N Washington Street, Ste 234 Falls Church, VA 22042, (703) 532-3303

**WASHINGTON** PLAN of Washington 24226 9th Ave S Des Moines, WA 98198, (206) 878-2562

This list of PLAN programs was obtained from the National PLAN Allance, For more Information, contact National PLAN Alliance, 195 Woodlawn Ave, Saratoga Springs, NY 12866; (518) 587-3372 (voice/fax).

MATIONAL INSTITUTE ON LIFE PLANNING FOR PERSONS WITH DISABILITIES The National Institute on Life Planning for Persons with Disabilities (NILP) is a non-profit organization affiliated with Sonoma State University. NILP serves as a netional clearinghouse for parents and professionals seeking the latest information about estate planning. NILP can provide information on a variety of topics including government benefits, legal issues, advocacy and guardianship and housing. It also provides a professional Training program and designation— Chartered Lifetime Assistance Planner (Chl.ap)—for professionals who want to LP provides workshops on all aspects of life planning to parents and profesdistionals, it does not provide any direct legal or financial services. Contact NiLP, Cilis, Sonoma State

Park, CA 94928-6922; (800) 854-

3343; (707) 664-4235; (707) 762-2657, fax.

UCUI

What are your concerns

about estate planning?

Readers with concerns or questions

about any aspect of estate planning

write to Estate Planning, c/o

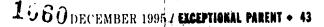
Involving a child with a disability may

EXCEPTIONAL PARENT, 209 Harvard St.,

Brunetti will answer reader questions

in upcoming issues of the magazine.

Ste. 303, Brookline, MA 02146. Mr.



continued from page 48

several qualities: trustworthiness, sensitivity to the physical and emotional needs of the child with disabilities and ability to handle the financial affairs of the trust. A trustee must act almost as a surrogate for the parent. In some cases, two trustees may be needed—one to administer the financial aspects of the trust and another to carry out the more personal duties of the trustee such as personal visits with the child and advocacy on his or her behalf.

In addition, the parents must have properly drafted "powers of attorney," which grant another person the legal authority to carry out their affairs if they become unable to do so. In this event, it will be important that another individual is ready and willing to take on the role of "successor legal guardian," a role that gives this person legal responsibility to care for and act on behalf of the child with disabilities.

It's only human to put off making difficult decisions, but in most cases, parents of children with disabilities will have started the estate planning process without necessarily labeling it as such. Most parents will have information needed for an "inventory" readily available--though perhaps not yet organized in a three-ring binder. Many parents have already drafted a "living plan"—in their minds if not in writing. Some parents may have already discussed the issue with an attorney. All that remains is some basic organization and a decision to complete the estate plan within a specific time frame. **EP** 

Frank L. Brunetti is an attorney and Professor of Law and Taxation at Fairleigh Dickinson University in Teaneck, New Jersey, and maintains a tax practice in Hackensack, New Jersey, Mr. Brunetti has written for the ESTATE PLANNING JOURNAL on the topic of estate planning for families who have children with disabilities. He also is an author and lecturer for specialized tax courses sponsored by the American Institute of Certified Public Accountants. He serves on the editorial advisory board of several tax publications.



## MEDIA

CEREBRAL PAISE A
COMPLETE GUIDE FOR
CAREGIVING addresses
the many complexities
and uncertainties. At

the same time, it provides the information parents, grandparents, caregivers and health professionals need—everything from medical, educational and psychosocial implications to wheelchair maintenance and dental care.

This book is available from Exceptional Parent Library (800/535-1910). The following is an excerpt from chapter two, "An Overview of Early Child Development."

## How may the development of a child with cerebral palsy differ from typical development in the first year of life?

Developmental delays are anticipated for the child with cerebral palsy (CP)... The child with cerebral palsy most often does not accomplish gross motor tasks at the same rate as the child without CP, for example. Differences in the pattern of movement may be seen as well. Due to increased tone, or spasticity, some children with CP may not be able to fully separate the movement of their heads from the movement of the rest of their bodies, making their limbs feel and look stiff when they are rolling, attempting to sit or trying to walk. The child who is "floppy," or who has low tone, may not be able to generate the forces necessary to hold his head up or roll in a smooth pattern. This child may slump when seated or placed to sit, and may buckle or collapse at the knees when attempting to stand.

In terms of fine motor skills, small muscles in the hand that are used to manipulate objects are often affected by tone imbalances in children with cerebral palsy. In children with spasticity, or increased tone, impairment may begin at the shoulder, with the inability to extend the arm to reach for an object. The hand itself may be less controlled in fine regulation of movement, making it difficult for the child to reach and grasp. In children with an athetoid component, the "fine tuning" required

to coordinate reaching, grasping and releasing may be missing.

The child with a known or emerging hemiplegic pattern may prefer to use one hand over the other... Hand preference usually doesn't emerge until about 18 menths, so if your child does not use both hands equally when he or she is younger than 18 months, you should mention this to your child's doctor.

Language development and problemsolving abilities are not necessarily affected in the young child with cerebral palsy, although language delay and mental retardation do sometimes accompany cerebral palsy. You need to be aware of normal nulestones and bring to the doctor's attention any behavior that is significantly behind what you perceive to be normal for a child of this age.

Many children with cerebral palsy are active and very social in the first years of life. A child with physical limitations, just like other children, seeks and needs verbal and physical affection in order for his personality and identity to develop. Visually impaired children, for example, often need more touching and verbal feedback than other children, since they can't rely on their sight to pick up a parent's soothing expressions.

You may find, however, that your child is less "huggable" and cannot return your embraces, but yo: shouldn't necessarily view this as your child's choice. A very small percentage of children with cerebral palsy exhibit autistic-like tendencies in the first year of life. These children appear to be in a "world of their own," neither seeking nor returning affection, eye contact or social contact. This behavior should be brought to the attention of the child's physician, and counseling may be initiated to help stimulate the parent-child interaction.

Excerpted from Cerebral Palsy: A Complete Guide for Caregiving by Freeman Miller, M.D. and Steven J. Bachruch, M.D. (with Marilyn L. Boos, R.N.; Linda Duffy, P.A.-C.; Douglas T. Pearson, Ph.D., Rhonda S. Walter, M.D. and Joan Lenett Whinston). Published by The Johns Hopkins University Press, 1995.

# A ELESS SEALV...





Epilepsy Foundation of America.

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#### **Membership Reservation Form**

150

It gives me great pleasure to give you a status report on the reauthorization of the Individuals with Disabilities Education Act (IDEA). The Senate Subcommittee on Disability Policy has held three great hearings on the IDEA where we have established a clear and compelling record of what the IDEA means to children with disabilities and their families. In July, we tackled the tough issue of discipline, holding a balanced hearing on what might be done to protect the rights of children with disabilities, while recognizing the responsibility of school personnel to maintain safe schools. Through the appropriations process, we are working to secure vital IDEA funding, specially for the state grant programs ande Parent Training and Information centers.

We will have a draft of the reauthorization bill for the IDEA ready for public comment on November 20. (To obtain a copy of the draft, contact the Senate Subcommittee on Disability Policy, 422 Dirksen Senate Office Building, Washington, DC 20510.) This legislation, when signed by the President, will be the blueprint that will guide educators' actions as they work with the special young people we care so about. This blueprint will open up new opportunities to children with disabilities. The effects of what we do will be felt into the next century.

We have spent many months reading and talking to people about how to best serve children with disabilities through the IDEA. As Chairman of the Senate Subcommittee on Disabilities, I laid out five major principles to shape the legislation:

- First, children with disabilities and their families should be the central focus of our drafting efforts.
- Second, if a current provision in IDEA works, don't undo it.
- Third, add incentives that encourage schools to serve children based on needs, not disability labels.
- Fourth, add incentives that encourage and prepare schools to include children with disabilities in school-wide innovation, reform efforts, and assessments of student progress.
- Finally, clearly link discretionary programs (federally-funded competitive grants for projects or research aimed at improving services for children with disabilities, conducted by universities, state boards of education or other agencies) to the state grant programs (federal funds provided to help states cover the excess cost of special education). With this link in place, discretionary grants will help educators educate children with disabilities and help families contribute in meaningful ways to the education of their children.

#### Specific examples

I want to give some specific examples of what we have done in our draft, examples that are consistent with my five principles:

In our draft, we have removed ambiguities with regard to parent participation in placement decisions affecting their child. Parents will participate, period.

In our draft, we have not changed the state grant funding formula. We have not removed the categories of disabilities that define a child's eligibility. I am in no mood to experiment with funding formulas or new definitions of what constitutes a disability. Such actions may have unintended consequences for children with disabilities and their families.

In our draft, we allow educational agencies to use IDEA state grant funds to coordinate services with other agencies to benefit children with disabilities and their families. We allow children without disabilities—when served along with children with disabilities—to receive the incidental benefit of state grant programs. I want school personnel to be empowered to help children without thinking about eligibility status. I want school personnel to be empowered to minimize the effects of and prevent disabilities with-

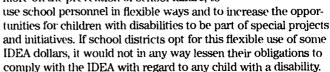
* For more information on how the IDEA reauthorization process may affect disciplinary procedures for students with disabilities, see "IDEA Reauthorization Update" (Networking, October 1995) and "Special Ed' Deserves Special Emphasis" by Rep. Randy "Duke" Cunningham (November 1995).

## The Reauthorization of the IDEA

by Sen. Bill Frist

out worry about a child's eligibility status.

In our draft, we give local educational agencies the option of implementing school-based improvement plans designed to benefit children with disabilities and their parents. I anticipate that this provision will help school systems to focus more on the prevention of school failure, to



Let me give one more example. In our draft, using multiple strategies, we make the discretionary grant programs catalysts and support systems for educational agencies and personnel who work with children. We require personnel grants, which fund personnel preparation and training, to better address staff shortages identified by states. We require that researchers make research results available to teachers more quickly. We give states the opportunity to compete for grant funds to tackle systems-change problems, such as how to include children with disabilities in state- and district-wide assessment of student progress.

In our draft, we retain the authorization and separate line item for the Parent Information and Training Program so these centers can continue their important work.

#### Discipline

Now for the \$64,000 question. We are working toward a bipartisan, multiple group consensus on provisions with regard to discipline. We are very close. Everyone has invested much time and thoughtfulness in bringing us to where we are today. This work will pay off. The discipline issue will not undermine a child's right to a free, appropriate, public education. I hope you will join us in the final steps to true consensus.*

#### Wonder, confidence, love and trust

As I think back over the last eight months, certain moments stand out for me. I remember making a few remarks at the NPND reception on a cold March evening. As I was about to conclude my comments, a little person with big, bright, beautiful eyes crawled across the floor to my feet. As I picked up that special little child, I saw many things in those eyes—wonder, confidence, love and trust. At that moment, I knew and understood why I accepted the chairmanship of the Senate Subcommittee on Disability Policy. My job, with your help, is to ensure that all children with disabilities experience wonder, develop confidence, and are loved by and can trust the people around them at home, in school, and throughout their special lives.

On November 8, 1994, Senator Bill Frist (R-Tennessee) became the first practicing physician elected to the U.S. Senate since 1928. Frist is a member of the Senate Budget, Labor and Human Resources, Commerce and Small Business Committees. He is Chairman of the Senate Subcommittee on Disability Policy. This article was adapted from remarks made by Senator Frist at the NPND Annual Meeting on October 2, 1995.

## QUESTIONS AND ANSWERS ABOUT

## **Managed Care**

by Family Voices

nce, the words "health reform" were on everyone's lips. Now we hear about "managed care." What is managed care? Is it health reform? Is it good or bad for children with special health care needs? Although "managed care" means different things to different people, this article will try to explain what most people mean by the term.

#### What is managed care?

Managed care is a way of providing pre-paid health care within a network that includes a specified group of health care providers and services. The network coordinates and refers patients to its health prc. iders and hospitals, and monitors the amount, patterns, cost and quality of care delivered.

Managed care differs from traditional "fee-for-service" plans, in which patients choose their doctors and other related services and pay for each service. Managed care plans usually limit the services patients may receive by making physician visits, therapies, home-care, pharmacies, specialists, clinics and hospitals available within their own system, and by using "gatekeepers" to prevent the provision of "unnecessary" services or excessive referrals outside the network. Managed care is not "health reform;" it is a way to finance and deliver health care.

#### How does it work?

Managed care plans are corporations —either for-profit or not-for-profit—serving large groups of people through a "capitated" system. This means that a business, school system, government body or membership organization pays the plan a set price for each employee's or member's health care coverage. The employer and employee usually share premium costs, and there might be a small charge (or "copayment") for each service. The physicians and providers in the network are on salary; they are not paid a fee for each service provided. Someone—often a primary care physician or nurse—is the "gatekeeper," deciding which services will be provided and whether referrals outside the network can be made. Keep in mind that "case management," in which an individual coordinates services for patients, is not the same thing as managed care, although case management can be part of managed care.

#### What are some examples of managed care?

- Health Maintenance Organizations (HMOs) are the most common form of managed care; all health services are delivered and paid for through one organization, often in a single location.
- Preferred Provider Plans (PPOs) offer a group of doctors and hospitals who give a discount on their services to an insurance company or an employer. In a PPO, consumers must choose their primary health provider from an approved list and must pay extra for specialty services received outside the PPO group.
- Medicaid managed care plans, adopted by many states, restrict Medicaid patients to a specified network of health care providers and services. States must obtain a waiver, known as an "1115 Waiver," to implement this kind of plan. (A waiver represents a situation in which a specific state applies for, and is granted, exemptions from standard Medicaid rules.)

#### Why is managed care considered so effective?

As health care costs have risen over the years, policymakers

and health economists have seen managed care as a way to save money. They believe that managed care plans—where everything and everyone is part of a controlled network—can achieve cost containment. Many health professionals also believe that a managed care system can provide care coordination and quality control.

### What happens to children with special needs under managed care plans?

Because many managed care plans are new, data about their effects on our children are scarce. However, there seem to be good and bad points. Possible advantages include the following:

- · Care coordination is easier.
- There are fewer out-of-pocket expenses.
- Health care needs are often taken care of in one place.
- · Unnecessary procedures are unlikely to occur.
- · Providers and services are closer to home.
- · Consumer satisfaction is often a priority.
- Continuity of care is likely.
   Disadvantages, however, also exist:
- There is a cost disincentive for making referrals to out-ofnetwork specialists for rare disorders or pediatric specialty care.
- "Gatekeepers" may lack knowledge and experience about some disabilities or specific conditions.
- It may be difficult to obtain access to specialty equipment, therapies, new medications or treatments.
- · Access to pediatric specialists may belimited.
- It may be difficult to get objective second opinions.
- In many managed care situations, it is unclear how patients and policymakers monitor the delivery of care, participate in patient and network decision-making and lodge complaints.

In general, it is important to remember that the expense of providing timely, appropriate and quality care to children with special health care needs may create a dilemma in a system that is based on cost-containment.

#### What should you do if managed care is offered?

Ask many questions: Who are the "gatekeepers" and what are their qualifications? Who are the pediatric specialists? Can you choose your own primary physician, pediatrician, specialist and therapist? Does the plan include the therapies, access to specialists and unusual treatments or medication your child requires? What will it cost to go to a specialist or provider outside the plan? Who gives and pays for second opinions? Is there a program or department for children with special health needs? Is there a consumer board, and what are its responsibilities and powers? How are doctor-patient decisions made? What are the grievance procedures? What state or federal body monitors the managed care plan, and are reports available?

Families should insist on the involvement of consumers in the network's policymaking, quality assurance and grievance procedures. **EP** 

Family Voices is a national, grassroots clearinghouse for information concerning health care for children with special health needs. Family Voices monitors public and private sector health care changes affecting children and families through the collective efforts of member families, a volunteer coordinator in every state, 10 regional coordinators and a small staff working in several locations around the country. For more information, or to share your concerns about managed care, contact Family Voices, P.O. Box 769, Algodones, NM 87001; (505) 867-2368; (505) 867-6517 (fax).

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## fathers Voices



## urviving

by James Elliott

arenting children with disabilities can be brutally difficult. Each of us must deal with this fact on a daily basis, though most of us find it hard to confront. How many times do you hear or read about this side of our lives? The harsh realities that find us privately raging against everything? The media usually offers inspiring, hope-filled stories about sick kids and their brave, loving parents. These stories don't paint a complete picture. Would reading any of these stories prepare the new parents of a child with severe disabilities for what lies ahead?

The lives we live as parents of these kids are routinely portrayed as a-okay, as long as we show a "positive atti-

tude." The truth gets lost in people's need to maintain a strong, socially acceptable, outward appearance. This need brings people too close to the edge of total denial.

In all honesty, it has been my experience that raising a child with severe disabilities is generally not enjoyable. This is not to say that good times never occur, but the times of true happiness are so few when compared to the times of sadness, pain, guilt, pity or all-out exhaustion. I am upset when people imply that I'm simply whining about my life. My feelings do not grow out of self-

pity or selfish regret; I have no room left in my heart for such things. My sadness and pain come from the anguish of watching my child suffer more often than not.

I love my son intensely, and I'm thankful that he is alive. But I refuse to pretend I'm at peace. I wouldn't wish my

Reese Elliott, at one week old, had dropped to one pound, 11 ounces. Here, his father holds his hand.

family's life on my worst enemy.

I've learned a lot from our experience, but I compare my feelings to those of a returning combat hero, standing under bright lights during some medal ceremony. The soldier stands there blinking, trying to accept accolades from the crowd, when inside all he knows is that he had to watch his buddy get his guts blown out on the battlefield. He knows he just happened to be the guy left alive to try to save his friend. This is not a peaceful knowledge. He knows he survived, that's all. There can be no peace with the rest, and no denial of the nightmare he had to live through—not until someone finds a way to set back time, to prevent that shell from exploding, to relieve him of the painful memories of a loved one's suffering.

My son, Reese, was born three months premature, after my wife went into spontaneous early labor for reasons doctors could never explain. She was in perfect health, did everything right, and Reese still came early. He was yanked from the womb weighing just two pounds, in an emergency c-section, and rushed to the NICU. There, he was hooked up to I.V. tubes, sensors and monitors.

The doctors told us to find the hospital chaplain. Before my son was a day old, I watched a priest give him his last rites. All I could ask was a simple question—what kind of God would allow this child to be born, just to suffer terribly for a day or less and then die? What possible good could come of this situation? I started to feel a deep anger, which, even now, I grapple with daily.

Reese surprised everyone and hung on through four gruel-

ing months of brain hemorrhages, spinal taps, transfusions, countless I.V. punctures, seizures, brain surgeries, eye surgeries, abdominal surgeries and more.

The end result of his suffering was severe. Reese will live with permanent blindness, cerebral palsy from the brain damage, an inability to swallow most foods (he is fed through a tube in his stomach), hydrocephaly (an inability of the brain to drain its own fluids—a plastic shunt in his head keeps him alive), microcephaly (stunted head and

brain growth), a seizure disorder requiring permanent medication, extremely limited physical ability (he can't roll over, crawl or walk) and a

I would step off a cliff with a smile on my face to prevent my son from suffering anymore. But the simple fact continued on page 50.

host of other medical problems.



Reese, James and Marchelle Elliott spent their first: Christmas together in the NICU at the St. Joseph Medical Center in Burbank, California.



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James and Marchelle celebrated Reese's first birthday with him.

continued from page 49

is that I am in for a lifetime of watching my brave little boy suffer in ways that will break my heart over and over again. This is true for most of you also.

Surviving this life is what makes an exceptional parent truly exceptional. It's not the love for your child—love is easy; it comes unconditionally for most parents. It's not the faith—my faith is shaken to the core every day. And it's not the caretaking—caring for any child comes with the territory. In the end, it's the strength to get up every single day and live this life through to the next day, one crisis at a time, even as many of us harbor the unique terror that we'll probably live to bury our children. It's about the ability to stand up and somehow deal with this, to work, to smile back at someone and say good morning, to understand humor and joy again, to live in a world where other parents, who just don't see the value of life, beat their children or leave them on doorsteps. All these things are exceptional to me now. All take conscious effort every day.

You do not have to accept this life with thanks and praise, but you do have to live it. The innocent child you created needs you to live it. For most of us, the pain and anger will not decrease with time. It will become a permanent part of us. It will destroy some of us; I've seen it destroy individuals, families, relationships and marriages. For those of us who survive, this pain only moves within us, from the front of our minds to the back, where it lives and lies dormant like a dark shadow of ourselves.

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (far). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

Circle #31

Just stay aware of the pain and don't feel negatively about yourself when it creeps up on you. It happens to the best of us now and then. You'll look in the mirror and find yourself staring into something dark, behind your own eyes, and you'll recognize it as pain. It's just under the surface, all of a sudden, as strong and real as you are.

Don't be afraid of it-pain is life. Too often, it's a large part of it. You need to allow yourself the freedom to acknowledge pain and vent it as it comes up. Others may find you jaded, distant, aloof or just plain different. You are. You exist on a level they cannot comprehend. It is a special plane of existence-you know when you meet someone else on that plane. It's in their eyes, and no words are necessary. It's in the eyes of every parent I've ever seen walking the halls of hospitals and emergency rooms. For me, it helps to remember that there's only one place that's free from pain and, thankfully, I'm not there yet.

Some of us try to attach some spiritual purpose to what we go through with our sick children. From the day Reese was born until now—he turned three this year my wife and I have tried to remain open to understanding our situation We have tried to find some good in it and we often do. Yet the bottom line is that we believe we will never understand why Reese has suffered so greatly for most of his three years. We have decided that if some greater purpose exists, its true meaning will elude us as long as we are in this life.

When I sit alone praying for my son, I sometimes pray with as much bitter confusion as faith. When I turn on the television because I can't sleep nights, I see children in Bosnia hit in rocket attacks, children in Africa starving to death, children all over the world suffering. At these moments I have to stop myself from cursing what is good.

Life is good. Life is of God. I believe it is inherently negative to curse what is of God, so I do not allow myself to do that. But I do not pretend to understand this world either, and I cannot simply accept it with a smile. The trick is to maintain faith that chaos is not the norm in the spiritual realm, though it is often all we can see from the earth. EP



James Elliot lives in Pasadena, California with his wife, Marchelle, and son, Reese, 3. James, an actor, is writing his first screenplay. He also works as a property manager and bartender. Marchelle is a member of numerous early intervention committees and provides support to current NICU parents. Reese will soon begin attending a four-day-a-week special education preschool program. His favorite activity is music; he loves to hum and clap along with his favorite songs.

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روريا

## ASK THE DOCTOR

by David Hirsch, M.D.

## **Atlantoaxial Instability**

My 10-year-old daughter has Down syndrome. She wants to participate in some of the track and field events in the Special Olympics. Before she can participate, her doctor needs to fill out a physical examination form. The form requests the results of a special x-ray to rule out "atlantoaxial instability," which I understand is more common in children with Down syndrome. My daughter has never had this type of x-ray before. She plays very hard and has always been very healthy. Her physical examinations have always been normal; she has had no abnormal physical findings or complaints.

What is atlantoaxial instability? Is this something I need to worry about? What are the symptoms of this condition? How often should my daughter be x-rayed? Are track and field activities safe for her?

There is some disagreement between physicians and various medical organizations about the diagnosis and treatment of atlantoaxial instability. Nor does everyone agree about its implications for individuals with Down syndrome who wish to participate in athletic activities. In answering this question, I will try to give my assessment of this currently controversial situation.

Atlantoaxial instability (AAI), also referred to as atlantoaxial subluxation, is a condition where there is increased mobility or movement between the first and second cervical vertebrae (segments of the spine in the neck). Various studies have estimated that this condition occurs in 10 to 40 percent of children with Down syndrome; 15 percent is probably most accurate. AAI is also found in some individuals with rheumatoid arthritis, abnormalities of the second cervical vertebrae or dwarfism.

AAI is usually diagnosed with x-rays of the cervical spine, but typically does not produce noticeable symptoms. Symptoms are usually seen only when subluxation (incomplete or partial dislocation) of the joint

In this column, David Hirsch, M.D., a pediaprician and member of Exceptional Parent's Editorial Advisory Board, answers questions from roulers. Dr. Hirsch is a partner in Phoenix Pellatries, Ltd. in Phoenix, America. He specializes in treating children with develspencial disabilities and coronic illnesses. Since In. Hirsch has not examined the child in question, parents need to review his uppertions will appropriate professionals ention of aposific products or medications illustrate sugges

ions; he is not endorsing any specific products: Send questio, s to: Ank the Ductor, Exceptional Pagent, Harmend Street, Saile 309, Bridge

between the first and second cervical vertebrae leads to injury of the spinal cord in the neck. An individual with this type of injury may tire easily or may have difficulty walking. Other symptoms might include neck pain, limited neck mobility, head tilt, clumsiness, sensory deficits (numbness or weakness in the arms or legs) and spasticity (abnormally increased muscle tone).

Individuals with AAI who experience trauma or severe injury to the spinal cord usually exhibit these symptoms prior to the traumatic injury. That is, trauma or injury rarely causes the initial appearance or progression of these symptoms. Fortunately, individuals with Down syndrome who have AAI, as disagnosed through abnormal x-rays, rarely show any observable symptoms.

However, the situation is hardly that straightforward. In some cases, individuals with Down syndrome who are asymptomatic (have no symptoms), and who initially have normal x-rays of the cervical spine, will have abnormal x-rays later on, typically within the next three to six years. Other asymptomatic individuals with initially abnormal x-rays will have normal x-rays later, usually within the next six years. In fact, this type of change (from abnormal to normal) seems to be more common.

Asymptomatic AAI, while common in individuals with Down syndrome, does not seem to be a significant risk factor for later development of symptomatic AAI. According to the American Academy of Pediatrics Committee on Sports Medicine and Fitness, x-rays of the neck may have some value, but they have not been proven entirely effective for identifying individuals who are at risk of developing spinal cord injury while participating in athletic activities. The Committee concluded that it is more important to identify those individuals who have symptoms that indicate the possibility of spinal cord injury resulting from AAI. That is, it may be of more value to find those individuals who have early symptoms of spinal cord injury-before it leads to more serious medical problems-than to do routine x-ray screening of all individuals with Down syndrome.

The best way to identify symptomatic individuals is through regular, routine physical examinations, especially prior to participation in sports. It is also important for parents to learn the early symptoms of spinal cord injury resulting from AAI. This will enable parents who observe such symptoms to obtain immediate medical attention for their child. Doctors may order x-rays of the cervical spine or, on occasion, CAT scans or MRIs to further evaluate symptomatic individuals.

It does not sound as if your daughter has any symptoms of spinal cord injury resulting from AAI. Assuming her physical examination is otherwise normal, track and



field should be a safe activity for her. For now, because it is required for participation in the Special Olympics, I would suggest that your daughter get an x-ray of her cervical spine to check for any abnormalities that might suggest AAI. The x-ray should not need to be repeated until your daughter reaches puberty, in three to five years, unless she develops any of the symptoms mentioned above.

Finally, although this is not an issue that affects your daughter now, if she is ever to have surgery involving her head or neck, many anesthesiologists and surgeons would recommend a pre-surgical cervical spine x-ray. If this screening detected AAI, doctors would take special care in positioning and manipulating her neck during the surgery.

More information on AAI may be obtained from The National Down Syndrome Society (666 Broadway, 8th Fl., New York, NY 10012; 800/221-4602; 212/460-9330; 212/979-2873, fax) and the Canadian Down Syndrome Society (811 14th St. NW, Calgary, AB, Canada T2N 2A4; 403/270-8500; 403/270-8291, fax).

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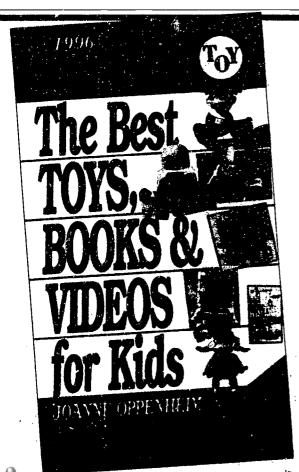
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## HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

## **Health Insurance Covers Only One Wheelchair**

Our health insurance plan allows for only one wheelchair per client, per lifetime. My child received a wheelchair at the age of four. When he was seven, we had to have the wheelchair adjusted at a cost of \$1,400. The insurance company denied the claim because they do not "repair, replace or adjust equipment." We are not eligible for California Children's Services (CCS)* because of our family income, so we paid for the adjustment ourselves.

We will eventually need at least one additional chair. Is there anything I can do to reverse the insurance company's policy of one wheelchair per client?

This is the first time I've heard **A** of an insurance policy that restricts its coverage of durable medical equipment to the purchase of one wheelchair.

Some insurance policies may exclude coverage for specific types of durable medical equipment. However, if an insurance policy provides coverage for such equipment, the policy usually allows for the purchase of new equipment when necessary to meet a person's changing needs. Since a child with a mobility-related disability is likely to need either a new wheelchair or an adjustment to his current wheelchair as he grows, the kind of restriction you describe clearly presents a serious economic problem.

The obvious solution is to try to find a new insurance plan that does not include such a restriction. If you are able to locate a new insurance plan, try to make sure it will cover your child's medical needs immediately. Unfortunately, many plans have waiting periods for "pre-existing conditions"-medical conditions already present before the purchase of the policy-and some plans never cover pre-existing conditions at all. Plans with pre-existing condition clauses often have waiting periods that range from six months to a year. If your new policy has a waiting period, ask your child's clinical team whether a local children's hospital may be able to loan out equipment temporarily, or whether you could rent appropriate equipment.

If you cannot find a new plan, you can explore several other options. First, your child's public school system may be willing to pay for a new wheelchair if it relates directly to his educational needs-if, for instance, there is no other way for your child to get from classroom to classroom. You would need to be certain that the need for the wheelchair is noted in your child's IEP (Individualized Educational Plan). You would also need to raise the issue of whether your child could bring the wheelchair home-equipment specified in the IEP to be purchased by a school system must sometimes stay in school, although rules vary from school district to school district. The school's IEP team can review its current rules with you.

Second, local charitable organizations, such as church groups and fraternal organizations, may help pay for medical equipment for a child with a disability. You might want to contact such community organizations, your clergy person or a family service agency in your area for assistance.

You might also search for a used wheelchair that meets your child's needs. Many people who have children with disabilities may be interested in selling or exchanging wheelchairs.

In addition, many people with wheelchairs they no longer need may be interested in donating those chairs. Many people who use wheelchairs, for example, are fully covered by their insurers for the purchase of replacement chairs. In such cases, an individual may eventually end up with two or three wheelchairs, since insurance companies generally do not want used medical equipment returned?

Unfortunately, I don't know of any national program that makes used wheelchairs available at this point. The idea certainly makes sense, however, and could be extended to other medical equipment, as well.

You might want to consider getting in touch with a parents' group to see if they are interested in creating a program for exchanging used wheelchairs and other medical equipment. You may also want to consider establishing such a program on your own. The American Self-Help Clearinghouse (Northwest Covenant Medical Center, Denville, NJ 07834-2995, 201/625-7101, voice; 201/625-9053, TTY; 201/625-8848, fax) has experience helping people set up support groups and has indicated their willingness to work with interested people to establish a nationwide equipment exchange program. EP

In this column, Richard Enstein anothers regions aucetions about head insurgence Sand graw que tions to him at Excurre PARTY NO B

* California Children's Services is a Children with Special Health Care Needs (CSHCN) program funded through federal monies (Title V of the Social Security Act) and matching state dollars. Currently, each state decides how CSHCN funds are spent, and services vary from state to state.

## Networking

Information from The National Parent Network on Disabilities

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## **NPND Holds Annual Meeting**



(left to right) Patricia MicGill Smith, NPND Executive Director; Justin Dert, clieability advocate; and Gene Nichener, inspirational humorist and NPND Annual Meeting keynote speaker.

From September 30 to October 2, 1995, NPND held its annual meeting at the St. James Hotel and in the halls of Congress in Washington, DC. One hundred parent leaders from across the country attended the meeting.

### REPRESENTATIVE CUNNINGHAM RECEIVES NPND PUBLIC SERVICE AWARD

Members of the NPND Board of Directors met with Representative Randy "Duke" Cunningham (R-CA), Chairman of the Early Childhood, Youth and Families Subcommittee of the House Committee on Economic and Educational Opportunities, which has been responsible for initiating the development of the reauthorization of the Individuals with Disabilities Education Act (IDEA). At the conclusion of the meeting, Joanne Butts, NPND president, presented Representative Cunningham with the NPND Award for Distinguished Public Service.

#### HEALTH CARE

Jack Ebeler, soon to be infirmed Deputy Secretary of Health, U.S. Department of Health and Human Services, spoke about proposed cuts to Medicaid and Medicare. These cuts, Ebeler explained, would render the programs incapable of meeting the needs of people with disabilities and senior citizens.

#### NYMB ELECTS NEW MOAND MEMBERS

MPAD has elected six new Board members. They are:

- Namey Bloki, STEP
  (Support and Training for Exceptional Parents),
  Gradinavilla, Tannassee
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Marty Ford of The Arc, Christina Metzler of the American Occupational Therapy Association and Barbara is T of the Federation of Families for Children's Mental Health, expanded on that discussion, addressing a wide range of issues including Medicaid/Medicare and mental health legislation.

#### THE ISTOOK AMENDMENT

David F. Arons of the Independent Sector, an organization that lobbies on behalf of non-profit organizations, explained the details of the Istook budget amendment, which is designed to limit the "political activities" of non-profit organizations and would prohibit them from providing any information about public policy or legislation. This amendment would severely limit the ability of PTIs (Parent, Training and Information centers) to inform parents about legislation affecting the educational rights of children with disabilities.

#### REAUTHORIZATION OF THE IDEA

A panel of staff members from the House Subcommittee on Early Childhood, Youth and Families

and the Senate Subcommittee on Disability Policy updated meeting participants on the status of the IDEA reaul norization in both the House and the Senate, Both House and Senate planned on producing a draft of the bill before the end of October. (EDIton's Note: The House issued their draft of the bill on October 30, and the Senate anticipates releasing their draft on November



(left to right) Carol Blades; Special Education Action Committee, Alabama; Connie Hawkins, Exceptional Children's Assistance Center, North Carolina, and retiring NPND Board member; and Martina Ziegler, TAPP (Technical Assistance for Parents Programs), Boston, Massachusetts.

20. Parents need to be informed and involved. For information about drafts of these bills, contact your local PTI; NPND can direct you to that PTI if you do not know how to find it.)

#### THE ROLE OF PARENTS

Judy Hermanii, Assistant Secretary of the Office of Special Education and Rehabilitation Services (OSERS); Tom Hehir, Director of the Office of Special Education Programs (OSEP); and Bob Williams, Commissioner of the Administration on Developmental Disabilities, U.S. Department of continued on page 56



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continued from page 55

Health and Human Services, called for a renewed commitment, from purerus to continue working for the educational rights of their children. NPND staff members Patricia McGill Smith, Executive Director, and Larry Searcy, Associate Executive Director, asked participants to evaluate the interest and energy of parents in their local communities for this type of active advocacy. NPND hopes to use this feedback to shape its strategies for the future.

#### THE DISCIPLINE ISSUE

NPND briefed key Senate and House staff members on their concerns about the reauthorization of the IDEA. Senator Bill Frist (R-TN), Chairman of the Senate Subcommittee on Disability Policy, opened the briefing. (For the full text of his remarks, see "The Reauthorization of the IDEA," p. 46) After his remarks, NPND presented Senator Frist with its Award for Distinguished Public Service.

A panel of parents then met with Congressional staff members to voice concerns about the potential effects of discipline proposals now under consideration. Pat Morrissey, Majority Staff Director of the Senate Subcommittee on Disability Policy, and Robert Silverstein, Minority Staff Director, joined the panel to discuss the process of trying to reach a consensus about the discipline issue.

The discussion focused on proposed changes to the current "stay-put" doctrine of the IDEA. Currently, in the case of a disagreement between parent and school district, a student can remain in his or her current placement while due process runs its course. The House proposal would assure that once parents opt to exercise their Constitutional rights to due process, their children would be "put out" of regular placements and put into alternative placements while due process ran its course.

Once the House and the Senate have both passed their own drafts, a conference committee, consisting of members of both branches of Congress, will meet to come up with a single version of the bill to be presented again to Congress and then to the President. Our best estimate is that this bill will be on the President's desk within the next 60 days.

To make your opinions heard, contact Representative Cunningham, Chairman of the Early Childhood, Youth and Families Subcommittee (2181 Rayburn House Office Bldg., Independence Ave. and S. Capitol St. SW, Washington DC 20515); Senator Frist, Chairman of the Senate Subcommittee on Disability Policy (Senate Dirksen Office Bldg., Rm 422, 1st and C Sts. NE, Washington, DC 20510); Senator Nancy Kassebaum (R-KS), Chairperson of the Senate Labor and Human Resources Committee (Senate Dirksen Office Bldg., Rm. 428); and Representative William Goodling (R-PA), Chairman of the Economic and Educational Opportunities Committee (2181 Rayburn House Office Bldg.).

#### "My pamily does revolution"

Disability advocate Justin Dart called for people with disabilities and their families to pull together across organizations, ages, disabilities, political parties and other narrow interests to build a "revolution of rights." "Some families have hobbies, and

some families do sports together," he explained. "My family does revolution."

#### **AWARDS**

NPND presented awards to Paula Goldberg and Counie Hawkins, outgoing NPND Board members, for their years of distinguished service to children with disabilities and their families. NPND also honored Gunnar Dybwad, Professor Emeritus of Human Development at Brandeis University, for his leadership in the field of disability rights throughout the world.



(left to right) Sue Pratt, CAUSE, Michigan; Paula Goldberg, PACER Center, Minnesota and retiring NPND Board member; and Judith Plackin, Parent Information Center, New Hampehire. "The finest publication of its kind.

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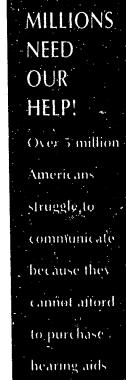
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• Boys With Fragile X Syndrome is a children's book designed to educate peers, classmates and siblings about the characteristics of fragile X syndrome. The book is the first in a planned series and can be ordered from the National Fragile X Foundation, 1441 York St., Ste. 303, Denver, CO 80206; (800) 688-8765. Cost is \$10, includes shipping and handling.

- Welcome to God's World is a free publication from the National Apostolate For People With Mental Retardation (NAPMR) that focuses on the initial concerns of parents after their children have been diagnosed with a disability. The booklet offers parents information about mental retardation, its impact on the family and a listing of resources. Contact NAPMR, 4516 30th St. NW, Washington, DC 20008; (800) 736-1280.
- Planning Your Dreams: A Roadmap for Life After High School for Students with Disabilities and Their Families is a guide that offers parents and students ideas to begin planning for life after high school. The publication focuses on Minnesota but also has useful information for students living in other states. Contact Minnesota Educational Services, 70 County Rd. B2 West, Little Canada, MN 55117; (612) 483-4442. Cost is \$4.50 (\$4 for MN residents), includes shipping and handling.
- The 1995 Directory of National Organizations of and for Deaf and Hard of Hearing People identifies 68 national consumer, service and professional organizations serving people who are deaf or hard of hearing. This free guide can be ordered from the National Information Center on Deafness, Gallaudet University, 800 Florida Ave. NE, Washington, DC 20002-3695; (202) 651-5051 (voice); (202) 651-5052 (TTY).
- Answering Your Questions About Spina Bifida is a comprehensive guide covering many medical and non-medical issues for parents and children with spina bifida. Contact Spina Bifida Program, Children's National Medical Center, 111 Michigan Ave. NW, Washington, DC 20010; (202) 884-3092. Cost is \$4, includes shipping and handling.

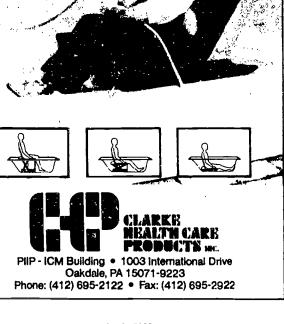


#### **Infant Studies Conference**

The International Society for Infant Studies will hold its biennial conference April 18–21, 1996 at the new Westin Hotel in Providence, Rhode Island. Special workshops will be held on April 18, including one sponsored by the University of Miami Touch Research Institute, and another by the Boston Institute for the Development of Infants and Parents. For more information, contact Prof. Lewis P. Lipsitt, Dept. of Psychology, Brown University, Providence, RI 02912; (401) 863-2332; (401) 863-1300 (fax).

#### **Needed: Air Travel Stories**

Access to the Skies, a program of the Paralysis Society of America (PSA), wants to hear from travelers with disabilities about their air travel experiences. They are collecting information to find out how well airlines and airports are complying with the Air Carrier Access Act by accommodating travelers with disabilities. If you have flown recently or plan to fly soon, call PSA at (800) 643-8245, 8–4:30 (central time), Monday through Friday, or participate in the survey 24 hours a day by visiting their Internet web site at http://computek.net:80/access95.



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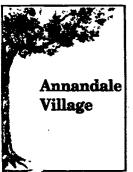
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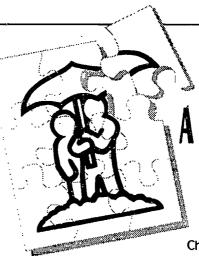


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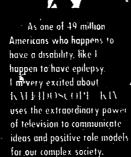
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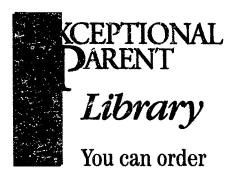


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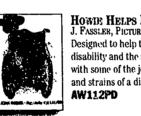
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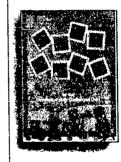


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## CHILDREN'S PAGE

## A Really **Neat Brother**

**By Christopher Brown** 

y name is Christopher Brown and I am nine years old. I have a brother named Patrick, who has bright red hair and is 17 years old. Patrick likes to watch TV, listen to music, dance and play games with me. He can't run very well, but he walks fast. He has trouble

talking, but he has a great smile. He has a disability called cri-du-chat syndrome.

When we go out into the community, people stare at Patrick because he sometimes acts differently. This makes me feel sad because he is a really neat brother. I admit that he sometimes gets on my nerves, and I wish he didn't have to act the way he does. But

> Patrick is a very sensitive brother—he knows when people are looking at him strangely and making fun of him.

I wish everyone would love my brother like I love him. I wish all other kids would like him also. People need to be taught how to act with others who are different from them. We need to teach others that people with disabilities are good people, too. If each of us would just show one other person that people with disabilities have many abilities, what a great world this could be. EP



Christopher and Patrick share a joke. Chris says he loves to make his brother Lugh.



Patrick went on his first date-to the high school prom with his girlfriend. Christina. "He was so excited!" writes his mother.

Twas the season! Eleven-year-old Patrick and three-yearold Christopher celebrated Christmas

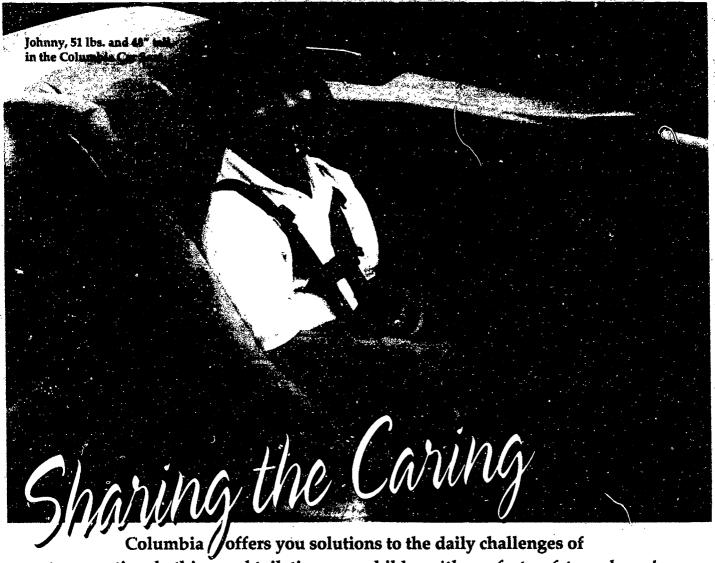
Christopher, 9, lives with his parents, Patricia and Dewey, and his brother, Patrick, 17, in Richmond, Virginia. Patrick has cri-du-chat syndrome, a chromosomal disorder involving a deletion of the short arm of the fifth chromosome (5p-).

Christopher wrote this piece in response to an invitation from one of Patrick's case workers to express some of his concerns about his brother. Christopher is in the fourth grade at Fisher Model School in Richmond. He enjoys computer games, TV and soccer.



"he Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: Children's Page, Exceptional Parent, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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